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THE ROLE OF THE SELF- ADVOCACY SUPPORT-WORKER IN UK PEOPLE FIRST GROUPS:

Developing Inclusive Research

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ABSTRACT

This thesis examines the role of self-advocacy support-workers in People First Groups within the UK. The study is undertaken through a process of inclusive research and involves a team of researchers from Carlisle People First.

The research discovered that the self-advocacy support-worker role is ambiguous and contradictory. Current government policy and indications of the early formation of a social movement, suggest the role is likely to be enduring and therefore in need of being called to account.

Support-workers and members, although in agreement with many of the central aims of self-advocacy, were often unaware of the multiple and conflicting requests made upon the support-workers by different individuals and organisations. The study sets out main areas of analysis and scrutiny of the role. The research provides empirical evidence for the possible development of the role based on the perspectives of both advocacy support workers and group members.

The work on developing inclusive research highlights the benefits and problems of a qualitative team approach. The research challenges current assumptions that there are areas of the research cycle too difficult for people with learning difficulties to genuinely participate in. It is argued that methodological rigour need not be compromised and that person-led, team research can indeed improve aspects of validity and reliability.

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This thesis is dedicated to the memory of my little sister, Anna Marguerite Fields.

CONTENTS

Abstract	2
Acknowledgements	3
Contents	4
Tables and figures	8
Appendices Index	9

CHAPTERS

1	Introduction: Self-Advocacy Support and Inclusive Research.	10
	The importance of self-advocacy support	10
	My journey into self-advocacy supporter research	12
	Introducing the research team	14
	Developing the approach to research	15
	Definitions and terminology	15
	How the thesis is structured	17
	Conclusion	19
2	Context: The Policy and History Relevant to Self-Advocacy Support	20
	Current policy context of self-advocacy in the UK	21
	How the current policies on self-advocacy inform this research	26
	The changing role of supporters in the history of the	
	Self-advocacy movement	27
	The early supporters	28
	The early supporters in the UK	30
	The changing role of support	32
	A more contested and ambiguous role of self-advocacy support	34
	How the history of self-advocacy support informs this research	36
	Conclusion	37
3	Literature Review: The Theories and Guidelines Informing Self-Advocacy Support.	38
	1. Main theoretical perspectives	39
	Normalisation, SRV and impact on the development	
	of self-advocacy	40
	The social model of disability	51
	How these theories affect the work of advocacy support	
	workers	60

	2. The task of advocacy support: How do workers learn about their role?	62
	Ownership and access	63
	Evolution of a supportive model	68
	Impact of social inequalities	73
	Relationship to professional standards	74
	The perspective of advocacy support workers	79
	Critique of the practice literature	82
	Conclusion	84
4	Methodology: The Development of Inclusive Learning Difficulty Research.	86
	1. The background of qualitative research in the field of learning difficulty studies	89
	Early qualitative studies in learning difficulty research	91
	The influence of feminism on qualitative learning difficulty research	96
	The influence of participatory action research on learning difficulty research	100
	2. Focusing on inclusive, participatory and emancipatory research in disability and learning difficulty studies	104
	Emancipatory research	106
	Participatory research	111
	Conclusion	122
5	Methods: Developing Inclusive Learning Difficulty Research within the Research-Team.	124
	Introduction	124
	Clarity of roles- individual skills and agreements	126
	Learning skills of research and people's own interests	129
	Agreements over methods in the team	132
	Deciding who to research and establishing an ethical approach	136
	Piloting the project- the importance of reflexivity	150
	Incorporating feedback from the pilot	153
	Reflecting on research relationships in the pilot study- power in the field	153
	Reflecting on Research Relationships- power and the research team	156
	Inclusive research methods in practice	158
	A case study of how the team prepared for work in the field	168
	Supporting the team in data analysis	169
	Conclusion	174
6	The Role of The Support-Workers in Self-Advocacy Groups: Perspectives Of Support-Workers.	177
	Background context	178
	The advocacy support-workers	180

	Support-worker perspectives of their role	181
	Advocacy support-worker journey into the job	181
	Models and theories	186
	What advocacy support-workers should do	192
	advocacy support-workers in action and emerging	
	Barriers	201
	How the process of empowerment worked	213
	Issues around funding	218
	Training and supervision	221
	National issues	224
	The difference between service advocacy and grass	
	roots advocacy	227
	Conclusion	230
7	The Role Of The Support Workers In Self-Advocacy Groups: Perspectives Of Group Members.	233
	The People First members	233
	Members journeys into their groups	236
	Models and theories	242
	What members think advocacy support-workers should do	246
	Support as understood by members and relationships with	
	advocacy support workers	249
	Views on power and the process of empowerment	252
	Members views of issues around funding	259
	Members ideas around training and supervision	260
	Members understanding of national issues	261
	Do members see a difference between service and	
	grassroots advocacy?	263
	Conclusion	265
8	Discussion: Perspectives Of Advocacy Support Workers and Group Members.	269
	Commonalities between perspectives	269
	Differences between perspectives	270
	Communication, access to information and inclusion	272
	Individuals versus the group	282
	Models and theories	242
	A People First model	289
	Social movement	295
	Management issues	299
	Support process	301
	Power and empowerment issues	303
	Managing change in groups	305
	Conclusion – what light does this shed on the purpose of	
	self-advocacy groups?	306
9	Reflections on Working as an Inclusive Research Team	315
	Rationale for team research	316

	Learning about research	318
	Learning skills of research within the project	318
	False starts	319
	Framing the project	325
	Preparing for fieldwork	327
	After the fieldwork	329
	Roles and relationships	330
	Comparisons	347
	Supporting Research	348
	Analysis	351
	Practical issues	356
	Accessibility	358
	Conclusion	360
10	Conclusions	362
	a. The role of the advocacy support-worker	362
	What was already known about the support role	363
	What the findings suggested	364
	What are advocacy support-workers perspectives of their role?	365
	What are People First members perspectives of the support-worker role?	368
	What both sets of perspectives indicated about the advocacy support role	371
	What light does this shed on the purpose of self-advocacy groups?	373
	b. The knowledge gained from working in inclusive research	377
	Major findings of the research process	377
	Things that could have been done differently	380
	Models of research	384
	Bibliography	387
	Appendix	420

TABLES AND FIGURES:

Table 1:	Breakdown of Data collection	159
Table 2	Number of interviews	166
Table 3:	The details of advocacy support-workers	180
Table 4:	The tasks of advocacy support-workers from the job descriptions	194
Table 5:	The contrast between contractual and reported tasks of the advocacy support-worker	201
Table 6:	Details of the members of People First	235
Table 7:	What good support is	247
Table 8:	What bad support is	248
Table 9:	Taxonomy of ‘person-led’ research	380
Figure 1:	Taxonomy for observing power relationships	162
Figure 2:	What is People First?	291
Figure 3:	Action and Process of People First	293
Figure 4:	Reflexivity over the different roles within advocacy support-work	313
Figure 5:	Summary of team discussion on the research process	324

APPENDICES INDEX

APPENDIX

1. Members of the Carlisle People First Research Team	420
2. Definitions of different types of advocacy.	421
3. Pictorial letter asking to visit group	422
4. Communiograms	425
5. Support-worker questions	426
6. Chapman 1997 questionnaire Northwest	427
7. Members questions for interviews	429
8. Pre-fieldwork meeting minutes	430
9. Graphic work from research group meetings	432
10. a) Analysis meetings	433
10. b) Themes from Group B analysis	434
10. c) Analysis Group B interview	436
10. d) Themes for analysis	437
11. Audit trail of fieldwork dates	438

CHAPTER 1

INTRODUCTION

Self-Advocacy Support and Inclusive Research

In this thesis I have investigated the role of the self-advocacy support-worker. These workers assist people with learning difficulties to organise and run their own self-advocacy groups within the UK. The methodological approach used in the research was qualitative and explored a participatory process of people working together as a Research-team. The team involved four members of Carlisle People First (see Appendix 1).

The introductory chapter sets out to explain why the subject of this thesis was of importance and why the topic was of critical interest to me. During the course of the chapter the terminology around self-advocacy and support is explained, defined and the research questions set out. The thesis focuses on two main areas:

- The role of the self-advocacy support-worker
- The development of inclusive research

The chapter ends with an outline of the overall structure of the thesis.

The importance of self-advocacy support

Self-advocacy, in the context of this study, is about people ‘speaking for themselves’ (People First, 1993, p.3), about their experiences and desires.

Although self-advocacy has a thirty year history in the UK never before has it

commanded so much attention as now, illustrated by a central focus in the White Paper, *Valuing People* (Department of Health, 2001).

Current U.K. policy and guidelines include numerous references to concepts such as ‘participation’, ‘inclusion’ and ‘hearing the voice of people with learning difficulties’ (see for example, *Learning Disability Taskforce Report*, Department of Health, 2004; *Making Change Happen*, Department of Health, 2003; *Advocacy Toolkit, Guidance for Partnership Boards*, Valuing People Support Team, Department of Health, 2003). Indeed, uniquely, *Valuing People* (Department of Health, 2001) was produced in consultation with people and their self-advocacy organisations (Walmsley and Johnson, 2003), placing people with learning difficulties at the centre of discussions. Therefore, in the current climate, hearing and understanding the voice of people with learning difficulties is a prime concern.

Advocacy support-workers are, generally, people without the label of ‘learning difficulties’, who are employed by self-advocacy organisations to assist their members run and control their own groups. Despite the current focus on self-advocacy, nowhere either in the literature or in policy documents is it described just how self-advocacy happens and how it can be effectively supported.

Similarly, discussion of the role of the advocacy support-worker is somewhat absent within the current policy and research context. It is my contention, therefore, that the role of the self-advocacy support-worker is a neglected topic and deserves further exploration.

This is despite the fact that advocacy support-workers have a place of pivotal importance in assisting people to run and organise their self-advocacy groups (Williams and Shoultz, 1982; Wilson, 1997; Goodley, 2000) and, therefore, in the development of self-advocacy as a whole. Hence questions needed to be asked about the role and how that role assists people in having a voice. Without this exploration and understanding it will be impossible to assess the role and comment on how to improve upon it. Because of these factors, the timing of this study was particularly appropriate.

My journey into self-advocacy supporter research

As a researcher I was uniquely placed to undertake this study. My interest began when I was twelve and my sister Anna was born. My journey alongside people with learning difficulties led me to become involved as a development worker with Carlisle People First in 1990. Therefore I acknowledge that I may be seen as an ‘insider’, as someone with experiences of how self-advocacy organisations work and develop.

I worked for ten years at Carlisle People First and over the course of my involvement met many other people involved in similar job roles. I noticed a lack of acknowledgement, discussion and scrutiny of the advocacy support-worker role throughout these years. Not only was there an absence of training and guidance, but also a pervading silence, a feeling that it was wrong to discuss the role because it took attention away from the main focus of the struggles faced by people themselves (Wilson, 1997; Walmsley and Johnson, 2003). Because of this, debate was stifled and training and development specific to the role, was scarce.

Self-advocacy group members were not support-workers and did not experience the role in the same way as advocacy support-workers, leaving it difficult to learn about the role from members. However, it seemed vital to me that support-workers remained flexible to the wishes of members, as they were employed to assist members control their own groups. Support-workers were, then, in the position of being employed (and managed) by the very people they were supporting, sometimes to an extensive degree. The multi-layered complexity and contradictions of the support work role began to emerge and become apparent throughout the thesis.

Recognition of the pulls in different directions on the support-worker mirrored the importance of being aware of the pulls on the researcher. As a person with declared ‘insider’ knowledge, there have been issues of partisanship to confront. Obviously there were tensions within this approach to research. There was a necessity to be clear about my own position, regarding the effects of prior knowledge through being a supporter, in relation to the people being researched. Reflective awareness was crucial throughout the whole research cycle and these issues are discussed in detail in Chapter 4. However, I argue that my distinct contribution to this area of research was to some extent facilitated because of my privileged position. This was not only the case for the subject matter about advocacy support-workers, but also for the workings of the Research-team (see Chapters 5 and 9) and access to the other groups to investigate. The quality and efficacy of the research was not, in my view, adversely compromised by the position I held due to constant self-questioning, the research training I undertook and the consistent support and guidance of my supervisors.

Introducing the Research-team

The Research-team members are of crucial importance to this project. Andy Docherty, Louise Townson, Malcolm Eardley, Elizabeth Harkness, Niall McNulty and I are all introduced in appendix 1. We have known each other for several years. Each person (excluding Niall) has their own research interest, which is derived from personal experience and concern, and each has been committed to the Research group for seven years. We met regularly as a team throughout the course of this particular research project to discuss and plan the work. In this thesis I have described how the length of time we have known each other has been of significance in the way the research has developed.

The Research-team were central to the project and without them there could have been no exploration of inclusive research. Further, as the thesis goes on to explain in detail, the case for using an inclusive approach was fundamental for a number of reasons:

- Development of academic knowledge around inclusive research
- Political and ethical approach towards research according to current disability theory
- Current government policy approach
- Importance of the insider perspective
- The self-determination of Carlisle People First

Developing the approach to Research

Indeed, when the team initially talked about the project it was decided that we would work on it together:

We [the team] talked about how the plan for research included many of the ideas that had come from the team, about people's life histories and what the groups think and feel. It took time to draw out the tangible benefits to the team, despite the fact everyone just said they were 'keen to be involved'. We talked about what may emerge at the end of it and the skills we would all learn along the way.

(Research Group (RG) meeting notes: October 30th, 2000)

The story of how the research developed, was challenged and subsequently changed is recorded throughout the thesis. The Research-team, through the course of the project, came to their own understanding of what the term 'inclusive research'¹ meant, and how it should be applied.

Definitions and terminology

Definitions and terminology in self-advocacy are contested and therefore it is important to clarify how terms are being used in this thesis.

There are a number of different definitions of advocacy, which are explained in depth in Appendix 2. In this project, the advocacy focussed upon is 'self-advocacy', which is about people speaking up and articulating their own views. Sometimes people need support and encouragement to do this, which is where the idea of an 'advocacy support-worker' emerged. People who form self-advocacy

¹ Inclusive research is discussed fully in chapter 4. In the context of the introduction it is taken to mean a way of researching that includes the involvement of people with learning difficulties in the research process.

groups, often go on to employ advocacy support-workers to help them run their organisations.

Broadly speaking, People First is the name of a particular type of self-advocacy group which affiliates itself, either formally or informally, to a loose set of principles around independence and being run by people labelled as having learning difficulties (People First London, 1993). People First groups are generally formed from grass roots membership and not tied into service provision of the Local Authorities. However, the research showed just how contested this assumption can be. A brief history of the development of People First and its supporters is given in Chapter 2.

In relation to People First groups, self-advocacy is often described as a ‘movement’ (Bersani, 1998) and this phrase is sometimes used. However the research also questioned whether self-advocacy is actually a social movement or not. It became clear throughout the study that the distinction was not always easy to sustain.

The term ‘advocacy support-worker’ is used throughout the text to highlight the difference between this and other types of support-work. For example, a support-worker may assist someone in his or her personal care, living at home, or in a hostel. Alternatively a support worker could be a member of staff who supported activities within a day-service. The blanket use of the term ‘support-worker’ may encourage unfounded expectations of the role. Therefore the term is clarified throughout the text.

The term used for people in the study who have been labelled as having *a learning difficulty*, is part of a heated debate that has continued for years. Many writers choose to use this term (Walmsley and Johnson, 2003; Goodley, 2001; Sutcliffe and Simons, 1993) because people themselves prefer it. The members of Carlisle People First Research-team were against the use of labels and pointing out differences between people (Carlisle People First Research Group, 2004). I have therefore used the team's preferred option of just 'people' wherever I can, otherwise I have used the term 'people with learning difficulties' when a distinction needs to be made for the sake of clarity. Any terms, other than 'people' are purely a label, and something that the Research-team prefers to reject.

Terms that have been avoided, because they were offensive to the Research-team, are 'user' and 'unit' and any other terminology that depersonalises the humanity of people. If the terms are found in the text they will be enclosed in inverted commas reflecting that it is a quote or concept from an alternative value base.

How the thesis is structured

The thesis is made up of ten chapters, starting with the Introduction. Chapter Two contextualises the area of study about the role of the advocacy support-worker. It sets the research against the backdrop of current policy relating to self-advocacy in the UK. The historical development of the role of the advocacy support-worker is documented revealing a changing understanding of the role.

Chapter Three reviews the literature around main theoretical underpinnings of support work in self-advocacy, i.e. normalisation, social role valorisation and the

social model of disability. It also analyses relevant empirical studies and guidance for advocacy support-workers, and identifies the gaps in the literature which have led to the main research questions.

Chapter Four outlines the development of inclusive learning difficulty research. It sets out the methodological context of the research and places the study within a qualitative framework. It traces the influences that led to the development of emancipatory and participatory research. It also starts to question the lack of involvement of people labelled as having learning difficulties in the holistic process of inclusive research.

Chapter Five begins to focus on the actual research project itself, describing how the team came to learn about the role of the researcher and the necessity for managing the research task around each person's strengths and abilities. It describes the necessity for reflexivity and awareness of issues of power.

Chapter Six relates to the first research question: **What are advocacy support-workers' perspectives of their role?** In this chapter I present my findings of their views.

Likewise Chapter Seven relates to the second research question: **What are People First members' perspectives of the support-worker role?** This chapter is largely devoted to the findings of the Research-team.

Chapter Eight discusses the two perspectives and questions some of the views held by both advocacy support-workers and members in the light of the evidence

collected in each group. The chapter relates to the third research question: **What light does this shed on the purpose of self-advocacy groups?** Some major barriers to effective support were identified and the idea of a new theoretical model is put forward that could better explain the workings of the groups.

Chapter Nine reflects on the second part of the research focus, which was about **the development, process, and merits of an inclusive approach to research.** It scrutinises the role each person played through the course of the research cycle. There is an analysis of the degree of participation and effectiveness of some of the methods used. The developments of the team's own ideas are also tracked, together with how they managed to take ownership of their own projects.

Chapter Ten draws together some of the main messages coming through the research. It identifies areas that would be approached differently in any future study and also points out what further study may be fruitful to take place.

Conclusion

This chapter has described the setting for the thesis. The research was about the role of the self-advocacy support-worker in People First groups, through a developing process of inclusive research. The subject matter is a surprisingly neglected area of investigation to which this thesis makes an informed contribution. The study was unique in contributing to knowledge around inclusive research through the development of a Research-team of people with learning difficulties and their participation in the research.

CHAPTER 2

CONTEXT

The Policy and History Relevant to Self-Advocacy Support

This chapter places the research project inside the broader arena of its subject area. This will help to ground and explain the role of the advocacy support-worker within a wider political and historical context. It will highlight why self-advocacy support is an important topic to be studying at this time.

The chapter illustrates that self-advocacy, has, for the first time, been called for by government and backed with funding, along with demands for the ideals of ‘inclusion’ and ‘participation’. Historically, it is shown that self-advocacy came to the UK through the enthusiasm of dedicated ‘allies’, the early support-workers. Although their work was crucial in establishing self-advocacy groups in the four countries of the UK, written documentation largely relies on the perspective of non-disabled people and, thereby, places them in a central role to the self-advocacy movement. However, as time has passed, it is possible that the voice of people with learning difficulties has influenced a change in the nature of how the role is represented.

For the purpose of clarity I have divided the chapter into two main sections:

1. Current policy and legal context for self-advocacy within the UK.
2. The history of support-workers within the self-advocacy movement of the UK.

1. Current Policy Context of Self-Advocacy in the UK

In this section I examine learning difficulty policy relating to self-advocacy in all four UK countries. Policy differs slightly and, given that the research covered groups in each of the four countries, it is important to set out the policy framework for each one. The policies in each country of the UK have a number of underlying values in common such as rights, independence, choice and inclusion (*Valuing People*, Department of Health, 2001; *The Same As You?* Scottish Executive, 2000; *Fulfilling the Promises*, National Assembly for Wales, 2003). They acknowledge the importance of advocacy.

It is against this current ‘official’ backdrop that the research project began. However, all of the groups visited within the research were active before the onset of any of the policies discussed below. This implied that the need for self-advocacy had gained a political reaction. Therefore it was also important to ground the project in an historical context.

Each country of the UK has its own relevant policy and thereby their self-advocacy organisations. In all countries, apart from Northern Ireland², the prominent point is that for the first time, government has funded self-advocacy. The four countries’ formal and informal policies that relate to notions of self-advocacy are:

²The situation in Northern Ireland is more complex because in October 2002, the Northern Ireland Assembly was dissolved with the breakdown of Stormont. This leaves questions hanging over the future status of policy and law in Northern Ireland.

- England *Valuing People: A New Strategy for Learning Disability for the 21st Century*, (Department of Health, March 2001).
- Scotland *The Same As You?* (Scottish Executive, May 2000)
- Wales *Fulfilling the Promises*, (Welsh Assembly, 2003)
- Northern Ireland *A Review of Mental Health and Learning Disability Services (Northern Ireland 2002)*.³

England

In England *Valuing People* (2001) called for more choice and control. Strategies mentioned were the development of advocacy; enabling more people to receive direct payments; and plans to move the 1,500 people living in long-stay hospitals to more appropriate accommodation in the community by April 2004 (Jacqui Smith, Minister of State, Department of Health, speech to the House of Commons February 1st 2002). The White Paper called for full participation, meaning that people should be involved in having a say in all aspects of their lives.

In terms of inclusion, the great difference between *Valuing People* (2001) and earlier White Papers, was that it involved people and their carers in the information gathering prior to the writing of the paper. The ‘Service Users Advisory Group’⁴ travelled throughout the country speaking to people about their lives and the services they received: information that was then reported back to the government. As Government Minister John Hutton (2001) remarked, ‘We have made huge efforts to involve the widest possible cross section of people with

³ Details of the publication of these policies are located in the bibliography under Department of Health, The Scottish Executive and the National Assembly for Wales.

learning difficulties in the way we have developed this policy' (p4). 'Including' people in the work of policy making has therefore been legitimised at a government level.

Further, the people involved in these Service User Advisory Group meetings were invited to take part in sessions to discuss how the White Paper could be made accessible to people⁵ (Walmsley and Johnson, 2003). This implied an acknowledgement that information needed to be drawn from, made accessible and known to people themselves, rather than just to their carers or workers, illustrating another change in the Government's approach. The Service User Advisory Group paved the way for a National Forum, made up of representatives from each of the nine regions of England. Four representatives from this group are linked in to the new Government Taskforce⁶, and along with professionals and civil servants, check on the progress of *Valuing People* (*National Forum Newsletter 1*, March 2003, p.5). Since the establishment of the National Forum, regional forums have also been organised. They provided space for people to represent their own views at government level.

The outcome of the concentrated work around self-advocacy and the National Forum (*National Forum Newsletter 1*, March 2003) impacted on self-advocacy groups, by seeking their involvement. The abundance of government initiatives with which self-advocacy groups can become involved, has in some ways become problematic to these groups, as highlighted later throughout the thesis.

⁴ This group was made up of representatives from People First London, Change and Mencap.

⁵ The accessible report '*Nothing About Us Without Us*' was published from this work (Department of Health, 2001).

⁶ The Taskforce also produces an annual report.

In terms of funding, the government made money available for the development of citizen and self-advocacy in England. This amounted to around £1.3 million, until 2004. The new figures for 2004-6 are £900,000 for each year, £250,000 of which has been ring-fenced for self-advocacy groups (Department of Health, Government Annual Report on Learning Disability, 2004).

Self-advocacy groups also obtain funding from health and/or local authorities. The Independent Advocacy Campaign (Holman, 2004) found that 21% of groups also receive money from the Community Fund, with 19% getting money from other charitable bodies. However, the majority of funding is very short term. Clearly, despite their growing importance in policy terms, there is much competition for the limited funds available for self-advocacy groups in England.

Scotland

In Scotland, *The Same as You: A Scottish Executive National Review of Services for People with a Learning Disability*, (May 2000), was issued before *Valuing People* (2001). The review was the first in-depth analysis of services for people in Scotland for over twenty years.

The review took an inclusive approach, by involving statutory agencies, ‘service users’, their carers, and people who deliver services. The review ran from December 1998 to December 1999 and gathered information about social and health care services for adults and children with a learning difficulty with a view to developing more innovative and person-centred services. After the review, a ‘blueprint’ for services was set out for the next ten years.

Scotland People First were involved as part of the Parliament's inclusive approach. Similar to *Valuing People* (2001), there was much concentration in the policy document on person-centredness and the importance of self-advocacy. Scotland People First, based in Edinburgh, were funded to develop groups around the country to represent their views. This illustrates the link between policy and the focus on service oriented advocacy.

Wales

In the wake of the pioneering All Wales Strategy (1983), policy making in Wales culminated in the consultation document, *Fulfilling the Promises* (2003). This document, similar to those of England and Scotland, covers areas such as person-centred planning and the call for developing self-advocacy. The Welsh Assembly is giving £1.1 million into the Advocacy Grant Scheme between the years 2003 to 2007 (Bild⁷, 2004). Therefore England, Scotland and Wales all have similar policy, and funding to back it up, albeit limited.

Northern Ireland

In Northern Ireland civil unrest had a marked effect on people's lives, especially on opportunities to develop independently and meet with others at night time (McConkey, private correspondence, 2002).

In 2002 the Department of Health and Social Services issued a *Review of Services for People with Learning Disabilities in Northern Ireland*, to be completed by the

⁷ British Institute of Learning Disabilities holds the current government contract for grants to Advocacy Groups. This funding was previously held by Values Into Action. See bibliography.

Summer of 2005. The Steering Committee included one parent and one person from a self-advocacy group. Similar to the frameworks in England and Scotland this review so far highlights the need for inclusion by access to mainstream services.

How the current policies on self-advocacy inform this research

Significantly the groups involved in this research study were set up before this recent government policy on self-advocacy emerged⁸. However the broad ideas of inclusion, that is, the call to involve people in developing policy, and the promotion of the concept of self-advocacy had been at the fore, it is clear that self-advocacy has a longer history than that shown through contemporary policy. This is discussed in the next section. The questions raised are i) does policy follow group activity or ii) does group activity follow policy? These are further addressed in Chapter 8.

Current policies highlight the need for self-advocacy and, crucially, back up this need with funding. However, the role of the advocacy support-worker appears to be taken for granted. There is no mention of the role in any of the countries' policies, simply a blanket assumption that advocacy support-workers are there, ready and able to undertake the task. There is no discussion of the support-worker role or any concern over recruitment, training or guidance. Therefore this is an area in need of research.

⁸ That is apart from, significantly, '*The All Wales Strategy*' of 1983.

Further, the main tenets running through current policy promote broad concepts of ‘inclusion’ and ‘participation’ of people in all aspects of society and services. It also highlights issues of information accessibility (although this is not mentioned in *Valuing People*, 2001). Consequently it is timely to be undertaking research that also develops an approach where people are involved in the whole process of the research task.

2. The Changing Role of Supporters in the History of the Self-Advocacy Movement

Whilst the support-worker or early ‘ally’ was crucial in bringing the concept of self-advocacy to the UK, there have been changes in the perception of the role (Goodley, 2000; Walmsley and Johnson, 2003). Non-disabled allies have written the majority of information about the rise of self-advocacy in the UK. However, there is a small body of literature from the perspective of people themselves. This literature tends to focus more on the intrinsic disadvantages of non-disabled allies and their role within the self-advocacy movement (Aspis, 2001; Bright, 2000).

Self-advocacy became established in the UK during the 1980s. The history of the development of the advocacy support-worker role is important because non-disabled people were central to bringing the concept of self-advocacy into the UK, as well as occupying an early ‘leadership’ role (O’Brien, 1987; Williams and Shoultz 1982). The theories that guided early supporters only shaped one prototype of the self-advocacy support role, that of a developer and leader (Goodley, 2000). The theoretical influences underpinning the role are fully discussed in Chapter 3.

The early supporters of self-advocacy were ‘champions’ or ‘allies’ and hence had certain clarity about their role. They did not work **for** self-advocacy or People First Groups alone, but were employed in other areas of (related) work, which linked into the development of self-advocacy. Today, supporters are employed **by** groups as their main job role and therefore have a different and altered role to the early champions. These adjustments from early champion to paid support are reflected in the changing title of the advocacy supporter discussed in Chapter 3.

The early supporters

Williams and Shoultz (1982) made (at the time) a unique contribution to knowledge and history of the self-advocacy movement, both in the UK and the USA in ‘*We Can Speak for Ourselves*’. Despite a number of texts written about the history of the self-advocacy movement (Bersani, 1998, Bourlet, 1998; Bright, 2000; Crawley, 1982, 1988; Goodley, 2001; Hersov, 1996), there is never a central focus on the role of support. Although some mention is made in passing, support is rarely highlighted as a main topic of scrutiny.

Notably, of the writers cited above, Williams and Hersov also acted as allies to early groups and assisted people to learn about self-advocacy, as well as writing about the self-advocacy movement’s history.

Who controls the writing agenda is an interesting point. It is clear that it is not members of self-advocacy groups who have written, or chosen topics to write about in this area. Nunkoosing (2000) has argued that that ‘one of the pervasive ways of marginalising men and women with learning disabilities is to deny them a

role in the construction of knowledge about our shared world' (p52).⁹ Therefore for the present project, it was vital to involve people with learning difficulties in finding out members' views about the support role.

There are some small differences in the detail of the history of the self-advocacy movement cited above, although there are overarching points to note. It is generally agreed that the starting point of the self-advocacy movement was in Sweden in the late 1950s to early 1960s, when courses were provided to teach people skills of decision making, committee work and voting, in order to run their own social and leisure clubs (Whittaker 1996; Kristiansen, private correspondence, 2000).

One of these groups presented parents with a list of requests about how services should be provided and this became the first known incident of 'group self-advocacy' (Shoultz, 1997, quoted in Goodley, 2000). It is worth noting that these 'courses' were taught which implied the presence of a teacher or supporter. This influence of 'teaching' had been developed with a number of groups, assisted by supporters, in writing about services and how they should be provided. Examples included *Our Plan for Planning*, by People First Liverpool and People First Manchester (1996) and *Oi! It's my Assessment*, by People First London (1993). Following the example of the Swedish courses, a three-day conference was held in 1970 for representatives from Sweden and Denmark. The news of this conference spread to other countries, including Canada and the USA (Whittaker, 1996). During the 1960s (Edgerton, 1967), and early 1970s, the large institutions for

⁹ This point was taken on board by the Research-team leading to their decision to carry on

people with learning difficulties in Canada and the USA were beginning to look at closure and towards a community life for residents. These conferences therefore came at a time when large numbers of people moved into the community.

In Nebraska, 'Project 2' was set up in 1975 (Williams and Shoultz, 1982, p.21); a self-help project from which emerged a local self-advocacy organisation.

Williams, (private correspondence, 2000) explained that following the State meetings, a State organisation was set up, chaired by Ray Loomis. The latter went on to write a poem which mentioned the words, 'People First', which have since become shorthand for independent 'self-advocacy of people labelled as having learning difficulties' throughout the world. At the time, professional people were identifying and supporting the need for self-reliance and the development of advocacy. In other words the impetus for the development of self-advocacy came from champions and allies, because they had the networks to do so, and ways of getting hidden voices heard.

The early supporters in the UK

To understand the reasons for the development of self-advocacy groups, and how intricately involved supporters were, it is helpful to look at the main points of the UK experience. According to Hersov (1996), a lot of pioneering work towards the development of self-advocacy within the UK was done by the Campaign for Mentally Handicapped (CMH), in the 1970s (see Shearer, 1972, 1973).

Ann Shearer, for example, was a Canadian journalist who helped form the CMH. She worked for the Guardian newspaper and reported on the Ely hospital scandal

in 1969, where gross abuse and neglect of people had been uncovered (Williams, 2000). Through her connections, participative conferences were held at Castle Priory College in Oxfordshire. The first one was called *Our Life*, held in 1972, followed by *Listen* (1973), and *Working Out, Participation and Mental handicap* (1973)¹⁰. The importance of these conferences (similar to the American and Canadian experience) were that they:

1. Involved people coming together to call for a greater voice and participation in decision making over the choices offered to people.
2. Were led and directed by people who were identified as *allies*.

By 1984, the first International Self-Advocacy Leadership Conference was held in Tacoma, USA, co-sponsored by CMH. This was an historic event for people from the UK, as Bright (2000) explained:

In 1984 America People First held their very first international conference for People First groups across the world. A group of people labelled as having learning difficulties from England attended to find out what People First was all about. They came back to England and established this country's movement.

Subsequently, People First of London and Thames was formed in October 1984 with John Hersov and Andrea Whittaker acting as advisors (Hersov, 1996). This is heralded as the starting point of self-advocacy groups in the UK. The term 'advisors' is interesting, because it encapsulates a particular view of the person with learning difficulties in relation to the supporter - a person with greater knowledge who is in a position to pass on advice. Again, this competes with some

¹⁰ For references see Shearer, A. (1972, 1973)

of the notions around self-advocacy support being presented today (see Chapters 6 and 7).

Overall the history shows that the place of the first supporters in the development of the self-advocacy movement was one of pro-active development and leadership, which relied in a great part on those people's networks with others across America, Canada, Scandinavia and the UK. The early supporters, or champions, were people who were employed in other posts but gave their time to help self-advocacy develop through the back up of their own connections. Three points that developments of self-advocacy had in common across the Atlantic and with Scandinavia were:

1. Institutions were closing and people were moving into the community
2. A number of conferences took place to focus on the issues concerning people with learning difficulties
3. The impetus for events to be held was in part a response to the abuse of people's human rights.

The changing role of support

Many of the early supporters of People First and self-advocacy groups in the UK (like those in Sweden and the USA) were professionals; people linked by their interest in challenging the poor treatment of people and influenced by the developing theories around normalisation.¹¹ O'Brien (1987) explained that early normalisation principles and self-advocacy development were initially analogous.

Indeed it could be argued (and Wolfensberger, 1999, does) that normalisation set the scene for the civil rights impact of later years, as well as setting the scene for People First to emerge.

The early supporters of the movement were involved in influential jobs; Ann Shearer as a journalist, Paul Williams as a campaigner, Andrea Whittaker as a project worker in the King's Fund¹², all of which helped networks of people to connect. For example, the King's Fund set up inclusive¹³ conferences and workshops, setting the scene for good practice across the country. People with learning difficulties started to be paid for their participation in events in the early eighties (Whittaker, 1996, p. 87). What these supporters did was provide a link between people and organisations, to enable them to have a voice within service structures. For example, in 1973 the Association of Professions for Mentally Handicapped People was formed to help break down professional barriers (Whittaker 1996), encouraging a more holistic perspective of the lives of those they worked for.

This was achieved through the power of supporters because, at this time, they were the only people placed in positions of influence that could make such changes. As such, it could be argued they formed the basis of an ideological shift, challenging traditional societal views of the worth of people (Shakespeare and Watson, 2002b).

¹¹ Normalisation is defined in Chapter 3 as creating 'normal' patterns of life for marginalised people.

¹² The Kings Fund in the mid-1980s was a UK Health Service Development Agency.

¹³ Inclusive, meaning involving people with learning difficulties in the presentation of conferences.

A more contested and ambiguous role of self-advocacy support

The influence of normalisation in the 1970s and early 1980s meant that people were perceived as individuals with impairments, but who could be assisted to be better placed to improve life chances. A lot of the work of early allies was about trying to improve conditions for people. By that I mean, these ‘impairments’ did not need to equate with a limited and abnormal life pattern (Nirje 1972), that was made very public by the hospital scandals. It is possible that with the rise of the social model of disability¹⁴ (see chapter 3), the benevolent practices of supporters from earlier times are more likely, if undertaken in today’s climate, to be viewed as paternalistic interventions. The social model highlighted the self determination of disabled people, and so people with learning difficulties shifted into a potential position of leading their own movement rather than being ‘followers’ of early supporters’ ideas. Hence the task of the self-advocacy supporter changed.

There is a small but growing critique of the role of the advocacy support-worker, by people labelled as having learning difficulties, most notably represented by Aspis. She raises interesting points about the difference between self-advocacy for people as individuals who are using services and self-advocacy within groups (Aspis, 1997; Simons 1992). Aspis feared that professionals use self-advocacy groups as a tool for their own purposes of refining and developing services, rather than focussing on important structural issues around power and control (Aspis 1997). In other words the role and motivations of people who are not labelled as having a learning difficulty was questioned. Aspis (2001) lamented:

¹⁴ Where society as a whole is perceived to disable people by various barriers to inclusion.

We attract support-workers who do not understand
any form of oppression...oh God!

Similarly, when Bright (2000) described the London group in 1984, he also pointed out that its main supporter was a professional – someone without a ‘learning difficulty’. He warned:

This was necessary to help with the development of the organisation. But there was a danger with this and that is the power to take over and control (p9.)

The tension between people labelled with learning difficulties and supporters was recognised at an early stage and is mentioned by Hersov (private correspondence, 2001). In looking back over the early 1980s, he states:

I remember that the supporters’ group met with reps. of the members’ group on occasion. Once, when the members felt we were ‘trying to take over’, they brought along as many of their peers as possible to make their case!

Bright (2000) went on to mention that:

People First’s special gift is that it is run by people with learning difficulties, not by professionals who do not have that label. People First National¹⁵ and People First groups for years have been using supporters. In 1993, People First National had co-ordinators who had learning difficulties, me and Alice Etherington. This was the first step towards People First National being run by the people who were supposed to run it – people labelled as having learning difficulties.

¹⁵ People First National is the new name for People First of London and Thames. This has been changed to reflect it’s new role, and government funding, to develop a National People First network across the country. Many groups feel that little consultation took place around their role. There has been conflict and debate over the ‘national’ issue for a number of years.

Therefore it can be seen that there are tensions around the role of the supporter that also have a long and established history, indeed, since the self-advocacy movement started in the UK.

Yet there has been little attempt to address these tensions apart from Dowson and Whittaker (1993, p.38) who held workshops for advisors to inform their book on the advisor role. They noted there was resistance from supporters around groups adopting typical organisational structures in the concern they would emulate the hierarchies and ‘power games’ of other organisations. However, despite this work, there has been no attempt at an inclusive appraisal. Bright’s comments also raise further questions that have been taken up by the Carlisle People First Research-team for their own future research: *Why aren’t people with learning difficulties acting as advocacy support-workers in People First groups?*

How the history of self-advocacy support informs this research

The information around history of self-advocacy support points to a changing view of the role of the supporter. The contested views place the advocacy support-worker in an ambiguous role. Far from the early supporters, who were actively linking people into their networks and teaching people skills, today’s advocacy support-workers are held in suspicion for not having the label of learning difficulty. This implies that there is a lack of clarity around their role, begs the question of what exactly they are there to do, and even questions if they should be there at all.

There is little to inform us as to what self-advocacy supporters experience in their role, because there are no published accounts by supporters about their role.

Similarly, there are no public discussions about the role. The thesis will therefore address this lack of knowledge around the role of the advocacy support-worker.

Conclusion

What this review has shown, and what this thesis explores, is the lack of information to draw on around the role of the advocacy support-worker. Although self-advocacy is clearly on the agenda at a government level, the supporter role is surprisingly taken for granted. Further, the history of the self-advocacy support-worker shows a shift from a defined championing and teaching role to a more ambiguous role that is now further subject to suspicion from the very people the supporter is there to support.

The call for ‘inclusion’ and ‘participation’ within policy, and from people about their movement, suggests that, quite apart from being relevant to the value base of People First, a participative approach to the research was essential. The terms are used very widely and it is not explained in the policy documentation exactly what is meant. In terms of this research, participation means that people with learning difficulties were involved in the whole process of research, and in the way that they decided to be involved.

CHAPTER 3

LITERATURE REVIEW

Theories and Guidelines Informing Self-Advocacy Support.

The literature review sought to uncover material that described and influenced the role of the advocacy support-worker. The previous chapter drew attention to the importance of the theory of normalisation, which was allied, according to O'Brien (1987) to the development of the self-advocacy movement. Therefore the first section of this chapter seeks to review the literature around the main theoretical underpinnings of support work in the self-advocacy movement. This also provides a context to review empirical studies and guidance for advocacy support-workers. My analysis aims to question what the theories encourage advocacy support-workers to understand about their role; where problems may lie, and what emerges as areas for further study.

The second section of the chapter looks at what sort of material would be likely to influence support-workers coming into the role. This exploration of perspectives can inform theory development. What appears to be missing is the influence of grounded empirical study, and equally importantly, the voice of people themselves as to what they are expecting and hoping for. In analysing the literature that is available, I am seeking to find the inferences that are made about the advocacy support-worker's role; how that links to theory and what that means for self-advocacy support-workers and People First members.

1. Main Theoretical Perspectives Informing Advocacy Support Workers

From the 1970s onwards, normalisation, that is, creating ‘normal’ patterns of life for marginalised people, and social role valorisation, (the theory that developed out of it), have been inextricably bound up with the development of self-advocacy (O’Brien 1987). Much of this theory was values-based and integral to it was the continuing role of non-disabled professionals (Walmsley and Johnson, 2003) as will be explained later. It was therefore of relevance to advocacy support-workers and their current position.

Latterly, the influence of the social model of disability (Oliver 1990; 1996) came to the fore, specifically in the literature relating to the lives of disabled people and to a more limited extent to the lives of people with learning difficulties (Mitchell, 1998). The limitations of the social model of disability (Shakespeare and Watson 2002a, Tregaskis 2002) have pointed theorists in the post-modern direction of identity theory and new social movements (Borland and Ramcharan, 1997, Finlay and Lyons, 1998). Some writers have started to look at the influence of the social model of disability on self-advocacy groups (Aspis, 2002; Goodley, 2000).

The theoretical underpinnings of the support role in self-advocacy, like self-advocacy itself are both complex and constantly evolving. However, what is missing is an exploration of the perspectives of support-workers and group members, which can both adequately inform theory generation, and provide practical guidance.

The discussion addresses each of the following:

- Normalisation, Social Role Valorisation and their impact on the development of self-advocacy
- The Social Model of Disability
- Impact on the work of advocacy support-workers.

Normalisation, Social Role Valorisation and impact on the development of self- advocacy

In Scandinavia, the principle of normalisation was developed in the late 1950s to early 1960s as a response to people who were socially isolated and institutionalised, often in massive ‘warehouses’ or hospitals for people labelled as ‘mentally subnormal’ (Banks-Mikkelsen, 1980). Nirje (1972, p.1) claimed that the normalisation principle meant it was **right** to make available to all people the same patterns and conditions of everyday living that were as close as possible to or the same as the ‘regular circumstances and ways of life of their community and culture’. However the ‘normal patterns’ of life were somewhat limited and contradictory as segregation of people with learning difficulties living and working in different places to the general public was not at this point questioned, as observed by later commentators (Emerson 1992, Brown and Smith 1992).

This emphasis on rights, but acceptance of segregation, was different to the development of normalisation in the USA (Emerson, 1992). The impact of the Civil Rights movement had led to expectations of people leaving long stay

institutions to live in the community, as affirmed by President J.F. Kennedy in 1963, (Szivos, 1992, p.4). Wolfensberger (1972), in developing the concept of normalisation, proposed a wider definition of normalisation:

Utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible (p28).

A problem with normalisation (that had been identified as a principle encouraging services towards ‘normal patterns of life’) was that it had the potential to be taken simply to mean, ‘making people normal’. By this interpretation poor practice and coercion of people occurred (Brown and Smith 1992, Race 1999). In the light of this Wolfensberger (1983) developed his ideas around Social Role Valorisation, (SRV), which he described as:

the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people (p.234)

For Wolfensberger (1998), SRV developed out of the principle of normalisation and was ‘...meant to subsume and replace it’ (p.1). He explained this was because:

...Since I have abandoned a normalization formulation in favor of a Social Role Valorization construct, the question of ‘making normal’, recedes into the background in favor of the question of whether someone’s social roles can be valorized (p.92).

SRV was a theory which attempted to explain why people were treated badly and devalued by society. It claimed that it could be tested empirically through the development of comprehensive evaluation tools such as PASS (Wolfensberger and

Glenn, 1978)¹⁶ and PASSING (Wolfensberger and Thomas, 1983)¹⁷, designed to test the practices of service systems. SRV also suggested ways that marginalised people may be helped to avoid negative outcomes and in this way was a dynamic theory.

SRV theory was also a meta-theory (Jenkins 2004). That is, it was based upon a number of other theories that informed it, such as labelling theory, deviance theory, identity theory and role theory. The basis of the argument (see Wolfensberger and Thomas 1983), is that the experience of devaluation occurred when groups of people were systematically treated poorly by society because of the differences between them, and people who were ‘valued’.

As a result of this approach, devalued people experienced ‘wounds’ (Wolfensberger, 1998, p. 82). These wounds, according to Wolfensberger, could be typified and predicted. They were allowed to happen by society, indeed may have been expected to happen to people who were devalued.

The ultimate wounds within services now are seen to be the wasting (and thereby shortening) of people’s lives (Wolfensberger, 1990, p.24). Wolfensberger developed contemporary ideas around themes such as ‘deathmaking’, where services and society, albeit unconsciously, developed policies and practices that

¹⁶ PASS stands for Program Analysis of Service Systems – A method of quantitative evaluation of human services. PASS was intended to be used only after an independent auditor had received thorough training on a 5-day workshop.

¹⁷ PASSING stands for Program Analysis of Service Systems’ Implementation of Normalization Goals – a method of evaluating the quality of human services according to the principle of normalization. PASSING is different from PASS because it does not focus on service administrative issues.

prevented people being born, enabled early infant death or removed people to institutions where they became socially dead.

SRV claims that those who were valued in society inhabited valued social roles (Thomas and Wolfensberger, 1999, p.126). By helping people who were (societally) devalued gain valued social roles, it was suggested that much could be done to counteract the dynamic of devaluation. Role circularity (Wolfensberger, 1972, p.16) was an important concept that was embraced by SRV because it explained why the **image** of people was of so much importance.

Thomas and Wolfensberger (1999) explained:

SRV proposes that people who hold valued roles in society are more apt than people in devalued roles to be accorded 'the good things of life' by their society. Consequently if people who are devalued by their society, or who are at risk of being devalued, are to be given the good things of life, then they should be helped as much as possible to fill roles that are highly valued in society. Otherwise they will probably be badly treated (p.126, my underline).

Note the words I have underlined that implied assistance **from** others to the situation of 'devalued' people. This was the crux of the theory; that other people (professionals, or even non-disabled citizens and/or those acting as citizen-advocates) were in a position to change the life experiences of people with learning difficulties. It is clear how it would be useful to advocacy support-workers, because it implied the necessity of their role in changing the life experience of the individual.

However this conception was not necessarily about self-determination. Clarke (1992, p.467) pointed out that there was a double bind of support versus control characterising the relationship of people with learning difficulties and their supporters. Edgerton (1967) also described the paternalistic relationship of ‘benefactors’, resulting in loss of autonomy. The point was about how much power a supporter could take without taking power away from a group member.

In terms of the position of advocacy support-workers, Wolfensberger’s earlier work on developing citizen-advocacy (1975) called for mature, competent volunteers to give freely of their time. Wolfensberger felt that citizen advocates, by giving freely of their time, would be in the unique position of being involved in a person’s life because they **wanted** to be there rather than **being paid** to be there. They were to have long term commitment, independent relationships and ‘rich social networks’ (O’Brien and Wolfensberger, 1979; O’Brien, 1987, p.3) In short the citizen-advocate role encouraged altruism by people, who in Wolfensberger’s terms, would be regarded by others as ‘highly socially valued’.

If this altruistic approach was translated into the advocacy support-worker role, it suggests that there would be expectations of very high levels of commitment, perhaps even blurring the boundaries between work and other aspects of a supporter’s life.

Wolfensberger saw citizen-advocacy as a necessary precursor to self-advocacy (Wolfensberger, cited by Williams and Shoultz, 1982). However in more recent years he became critical of self-advocacy, because he believed empowerment and

self-determination encouraged by advocacy support-workers was essentially damaging to people who actually needed protection (Wolfensberger, 2002).

Advocacy that is provided by another person, an advocate, who speaks for an individual, implies knowledge of the person's needs. But this knowledge is by its very nature second hand because it has to be interpreted by another person.

Wolfensberger (1999) said about residential services for people with learning difficulties:

Give them not what they say they want, but what they really need (p.70).

This suggested a marked difference from the views of disabled activists and, as Aspis (2002) pointed out, 'what people really want is usually not framed within...existing services'. Wolfensberger seemed to be implying that other (non-disabled and valued) people may know best.

Of relevance to the advocacy supporter worker role is whether they perceive themselves in a position to judge what is best for people, or, alternatively whether they understand their role as simply standing by the ideas of people with learning difficulties. This question points to an ideological difference in the approach and working practices of support-workers. For me, key issues around differences to be resolved were:

- advocacy **for** people with learning difficulties versus advocacy **by** people with learning difficulties.
- a stress on **impairment** of the individual rather than **societal barriers**.

Self-advocacy could be about speaking up as individuals (Sutcliffe and Simons, 1993), but it also had the potential to be about group perspectives of people's needs and therefore take a group focus on barriers within society. From this, self-advocacy based around a group perspective could potentially lead to the adoption of a collective identity (Chappell 1992). Identity is seen as a crucial aspect of a social movement (Bersani, 1998). But if supporters were framing people's needs (giving them what the supporter **thinks** they need), then it could be argued that supporters were framing people's identities, rather than facilitating self-determination.

Furthermore, the changes within services through normalisation and SRV being applied would not have occurred, according to Wolfensberger (1999), without the aid of 'vigorous champions' on both sides of the Atlantic. The word 'champions' denotes people who brought attention to, and developed ideas forward. Although it is not currently a popular notion, there is perhaps a mirroring truth for the development of self-advocacy and People First, as referred to earlier, in the championing role of people such as Paul Williams, Andrea Whittaker and John Hersov, to name a few.

There has been much criticism levelled at Wolfensberger's ideas from disabled activists. Wolfensberger's abundant writings and the manner in which he wrote have inflamed theorists from different perspectives. His manner can be typified by a comment that Wolfensberger (1999) made about his 'aha!' experience and how he was 'blown away' by the new ideas he encountered around normalisation and devaluation. He said that it was a real advance to find:

A single theory or principle that could be applied to all; not only to all retarded people and not only to all handicapped people but to all deviant ones (p.85).

However Mike Oliver (1999), an academic who is closely associated with the social model of disability said of this:

I vociferously denied the claim that the half-digested mishmash of functionalist and interactionist sociology we were being presented with had anything to do with our experiences as disabled people (p.167).

Note how this comment moved from academic debate to personal opinion. It was perhaps unclear to Oliver whether Wolfensberger was making a value judgement about people labelled as deviant, or if Wolfensberger was pointing out that a theory could envelop an explanation for all people who were discriminated against.

Liggett (1988), noted the constraining effects of developing oppositional culture to a normalising society: 'in order to participate in their own management, disabled people have had to participate as disabled' (p.271). This leaves questions about people who do not want to take on the mantle of their disabled identity.

Furthermore, to add to the complexity, discussion of disability and discrimination is emotive and highly charged precisely because it does touch on people's own lives and experiences and sense of power and disempowerment.

Because of these intense emotional politics, it could be suggested that voices from some sections may have been silenced, particularly those of (non-disabled) supporters, empathetic to disability rights but exposed when faced with the

conflicts and contradictions of their position. Advocacy support-workers could feel compromised because they are supposed to hold back and not take the lead, as ideas are presumed to come from members in self-advocacy groups (Sutcliffe and Simons, 1993; Worrell 1988).

Walmsley (2004b) called for supporters to take a more honest approach than the current 'passing and self-effacing mention' (p.2), which, she believed, had been influenced by normalisation and SRV(trying to set people with learning difficulties in the 'valued' role with the supporter in the background). Indeed throughout the literature, advocacy support-workers are noted by their absence.

What then is the role and position of supporters according to SRV? Wolfensberger (1999) fervently believed that the 'rights culture' was destructive and undermined the position of those most vulnerable in society, so it could be assumed that SRV's influence on supporters would not be prioritising fighting for rights. Yet Aspis (2002) stressed:

Parliamentary laws are necessary if permanent change, in the form of creating new rights for participating in society on equal terms, is to happen (p6).

Aspis claimed that self-advocacy, within the confines of services, created a 'false equality' and cited examples of the limited changes tolerated within services, for example, a change of curtains or a change of coffee machines. She argued that for changes to be effective they needed to be 'long term' where:

...it is necessary that the decision has been backed by rules,

policies or legislation so that it makes it harder for individual people in authority or institutions to take power back. (p5).

In contrast, Wolfensberger's work (1999, 2002), on the harmful nature of rights, centred on the difference between legal and transcendent (moral) rights. The argument ran that there were anomalies in law where certain groups were not included and thereby protected by the state, such as the rights of impaired newborns. In his view fighting for rights set groups of devalued people against each other. Further, radical rights were so individualistic that they harmed the very people they set out to protect. Wolfensberger (2002), argued:

The empowerment ideology would even encourage and 'egg-on' competency impaired people to demand whatever they want as their 'right', regardless of what the consequences might be on them or others of demanding such rights- or receiving them. In fact such 'egging on' is a major reality in the praxis of the contemporary empowerment cultus. (p256).

Wolfensberger argued that the quest for rights should never replace the exercise of justice and mercy. This may appear as a paternalistic view. He felt that protection of vulnerable people was required because people were not properly protected through legal rights and were dependent on a benevolent state. So would SRV indicate supporters should have a protective role?

Ideas around 'protection' can be problematic for People First groups who currently campaign to have law changed around capacity and consent and who may view and experience protection simply as 'overprotection'; as other people having control (People First National Newsletter, Summer 2003). The impact on the role of the advocacy support-worker was dependent on whether they saw

themselves as protective of people with learning difficulties because of their 'impairments' or whether they were working to enable people to take up and fight for their own rights. If they were standing beside people to fight for their own rights, were they 'egging on' people regardless of consequences? It seemed whichever position an advocacy support-worker took would be fraught with challenges.

In summary, the principle of normalisation and SRV could only have conceivably emerged from a top-down position, from professionals and academics rather than group members. SRV theory has continued its development without the inclusion of people with learning difficulties, both through lack of dialogue and abundance of jargon. This became a contentious issue to those working from a social model perspective (Chappell 1997) and those working within People First. There were further issues around accessible communication and 'jargon' for those working within People First that will be addressed later. Overall, it could be suggested that SRV allowed itself to remain an 'elite' theory by using language inaccessible to those whose lives it was about.

Although the principle of normalisation and SRV theory had been crucial to the development of self-advocacy (O'Brien, 1987) and therefore influential on the advocacy support-worker role, the literature showed that its continuing influence is contentious (Aspis, 2002). However 'pockets of belief' continue to co-exist as new approaches constantly evolve. Nunkoosing (2000) argued that:

Different knowledge claims and their related practices
are competing for our attention and we respond to this

by accepting the knowledge claim that best meets our needs at the time and consequently rejecting those claims that are seen to have outlived their purpose for us. (p56).

It should be noted that changes within services and the basis of the self-advocacy movement itself may not have been achieved without the influence of the principle of normalisation and SRV theory (Walmsley and Johnson 2003). Its continuing influence is evidenced by *Valuing People* (Department of Health, 2001) which could be argued as based on the foundation of SRV theory, and is even reflected in the name (Race 2002). However, despite it being a main plank of current government policy, it is not directly alluded to or given credit, which may reflect its current unfashionability. Race contends that:

‘The accepted wisdom in academic circles in England, [is] that SRV...is either finished or outdated...[however] there are signs of a small but growing interest in the theory from people involved in the mental health field, and also those involved with elderly people, and it may be through that channel that an alternative academic reaction can come’ (p.171).

The Social Model of Disability

The social model of disability was another powerful model cited by Goodley (2000) and Wilson (1997) in their discussions of the advocacy support-worker role.

The rise of the social model began in the 1970s when the Union of the Physically Impaired Against Segregation (UPIAS, 1976 pp3-4) made a distinction between impairment and disability in their ‘Fundamental Principles’ document. This distinction set out that **impairment** was to do with the confining limitations of the

body, be that due to a physical, mental or sensory impairment whereas **disability** was the disadvantage or restriction placed upon the individual by a society due to physical and social barriers (Barnes 1991).

This implied that disabled people were disabled by society, and challenged the legitimacy of the medical model to explain consequences by reference to individual impairments. The social model therefore looked to structures in society, which created and maintained discrimination. It has also been regarded as a life-defining concept (Tregaskis, 2002) and is described by Shakespeare and Watson (2002a, p12) as ‘the ideological litmus test of disability politics in Britain’. Perhaps because of this perception there have been generated an abundance of polarised arguments.

It is worth noting that this model was set at a societal level as an indicator of major barriers, rather than the predominantly individualistic cultural theory adopted through normalisation. The social model challenged so-called ‘normality’, whereas normalisation sought to replicate it and indeed enhance it through applied SRV, in the lives of disadvantaged people. In his critique of normalisation, Michael Oliver (1999) said that it:

...offers no satisfactory explanation of why disabled people are oppressed in capitalist societies and no strategy for liberating us from the chains of that oppression (p.164).

Following UPIAS, Finklestein (1981) formulated a Marxist critique of the position of disabled people in society. Oliver (1990, 1996), built on the work of

Finklestein, developing the Marxist materialist critique. He defined disability as a social construction of the society we live in. Oliver (1999) explained:

My own theorising on disability is located in Marxist political economy ...I would go further and argue that the social theory underpinning Marxist political economy has a greater transformative potential in eradicating the oppression that disabled people face throughout the world ...than normalisation which is at best a bystander in these struggles and, at worst, part of the process of oppression itself. (p.163)

Oliver (1999) claimed that disabled people readily accepted the social model of disability as it explained their experiences and quickly became integrated into disability equality training. But, he argued, professionals and services resisted the idea of the social model, at least initially, because they had a vested interest in continuing the role of ‘experts’ about other people, thereby upholding lucrative career structures (Albrecht and Levy 1981; Albrecht 1992; Nunkoosing 2000). This notion of career raises a relevant issue. The self-advocacy movement relies on employing advocacy support-workers. All the time people are dependent there will be work for supporters. From a social model perspective, this might suggest that advocacy support-workers are creators of dependency to maintain their livelihoods. Moreover, of relevance to support work is the reliance on the notion of ‘disability’ as a cover-all term, rather than ‘learning difficulty’ specifically. It raises a question as to whether ideas of the social model apply equally to people with learning difficulties.

In answer to this, Oliver (1999) argued that generically, disabled people **all**:

- share the existence of an impairment,
- experience oppression as a consequence and

- identify themselves as disabled persons.

If the individual disabled person came to understand they were disabled by society, then the person may begin to challenge that oppression and identify barriers to change. Jane Campbell (2002) related her experience of discovering the social model:

The principles locate the problem of disability with society – something we can change and improve. How liberated I felt when I realised I was not the problem and no longer had to apologise for my existence! (p.472)

This implies that disabled people can achieve political change through their own struggle, ‘that the struggle will be oppressed groups themselves against the forces that oppress them’ (Oliver, 1999, p171).

This internalising consciousness of oppression cited by Oliver is key to a social movement (Johnson et al, 1994). Freire (1970) a Brazilian educator, was also an influential thinker on this aspect of self-empowerment. He maintained that if an ally was to support a movement they needed to stand with oppressed people:

...True solidarity means fighting **at their side** to transform the objective reality, which has made them these beings for another. (1993, p 31).

Freire argued that if current societal structures remained, oppression would always take place. To translate this to the advocacy support-worker role would suggest being alongside people as allies, not working **within** oppressive systems. In turn, that would mean working as an ally within people’s own organisations, not as part of a dominant structure or its service system. This perspective has enormous

implications for the role of the advocacy support-worker or ally to a movement, as their role may be crucial in how they support people to bring about change.

Interestingly, Nunkoosing (2000) believes that much of the responsibility of change will fall on supporters.

The social model of disability, based as it is around the distinction of **impairment** and **disability** has failed to develop an encompassing and adequate theory for all sections of disabled people (Chappell, 1997). This has been the cause of long-standing debate. For example some theorists have questioned the lack of acknowledgement of multiple oppression on the grounds of gender, age, sexuality and race (see Morris 1991; Stuart 1993; Vernon, 1996). Furthermore, the disabling effects of impairment and pain are not taken into account (Morris 1991; Crow 1996; Hughes 2000) and in regard to this thesis, there is little explanation or exploration of the specific position of people with learning difficulties (Chappell 1998; Goodley 2001; Nunkoosing 2000; Coles 2001). There are issues around access to information and knowledge to consider as well as the many diverse and complex needs people may have. Fundamentally though, people with learning difficulties did not come up with the ideas of the social model themselves, which poses questions around ownership.

Oliver (1999) stated that he used the term, 'disabled people' generically, and that when he formulated his ideas he did not include an examination of the experience of people with learning difficulties. Despite this statement there is no further reference by him to the position of people with learning difficulties within the social model of disability. To Oliver, a specific 'impairment' is not a point of

essential importance. In his view, separating categories of disabled people would result in a fragmentation of the disability movement, something that he is against. Shakespeare and Watson (2002b) claim that debate has been stifled because the social model is such a powerful (and political) explanation for disabled people, that it has become a 'sacred cow'. Theorists loyal to the concept, because it is so tied into disability politics, warn against acknowledging diversity in the fear it will 'water down' the power of the social model (Barnes 1998; 1999; Finklestein 1996; Tregaskis 2002).

However, in this age of post-modernism, characterised by a fragmented and complex social structure (Oliver and Barnes, 1998), Shakespeare and Watson (2002), argued that the social model has become an outdated ideology precisely because of issues of impairment and identity:

For us, disability is the quintessential post-modern concept, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality. (p19)

They call for a new understanding of disability based around 'embodied ontology', where it can be perceived that everyone is impaired, not just disabled people. They suggest that the essential connection between impairment and embodiment should be further explored.

They used as an example people with learning difficulties, resisting being identified as disabled, which results in complicating the achievement of a collective disabled identity. This phenomenon of multiple identities (for example

being a person labelled as having a learning difficulty and also being visually impaired) is a discussion central to collective identity and the subsequent formation of social movements (Tregaskis, 2002).

As Sanderson et al (1997) claimed:

A sense of our own identity, of who we are, is crucial to all of us. It guides us in the decisions we make and the paths we take during our lives (p.64)

Goodley (2001) identified the complex factors involved in identity formation in a post-modern world. People's experiences are all different although there may be commonalities. Consequently, self-advocacy groups have a tendency to focus on personal as well as collective issues (Aspis 2000; Spedding et al, 2002). Drawing comparisons from the personal to the political for collective identity purposes is important for collective action. It remains to be seen whether this is a facet or aim of support work in self-advocacy organisations.

Clearly normalisation and SRV encouraged people to be supported to a 'valued' identity, just as the social model encouraged the view of a 'disabled' identity.

However as Shakespeare and Watson (2002) made clear, not all people who were disabled or had learning difficulties wanted to take on the disabled identity; some would rather 'pass' (Edgerton, 1967; Aull Davies and Jenkins, 1997; Finlay and Lyons, 1998) and try to minimise differences. This raises a question over whether a social movement (the self-advocacy movement) could form without a collective identity. In turn, this poses a further question around the self-advocacy support role. Indeed, social identity theory had been discussed in relation to people with

learning difficulties by a number of theorists (Atkinson and Williams 1990; Atkinson et al 2000; Finlay and Lyons 1998; Goodley 2000; Williams, 2002a).

Borland and Ramcharan (in Ramcharan et al, 1997) used the notion of ‘excluded identities’ as a heuristic device, (a device helpful towards learning). This brought together the idea of exclusion by society along with the development of the concept of self and identity. They suggested that the two are inextricably linked; if a person is excluded by society they will form an excluded concept of self and identity. This was clearly akin to role circularity in SRV theory. They also pointed out that each person is always in a process of ‘becoming’, which offers a more positive outlook in terms of possibilities, rather than a static identity.

There is little literature that tells us how advocacy support-workers view the identity of the people they work with, whether they see their identities as passive or static or changing (or if indeed they think about it at all). Ideally, from the perspective of Borland and Ramcharan (1997), development and supportive work within self-advocacy would involve helping a person adopt a more ‘included’ identity. This is not so different from supporting someone to achieve a ‘valued social role’. There is an example of this identity change in Docherty’s (2002) writing. He begins by describing his experience of the institution he lived in:

Inside was your territory because they would say you were out of bounds outside the gate. So on a Saturday or Sunday afternoon it was like a prison (p.145)

Then his testimony moved on as he reflected on his current situation:

People respect my position as Project Director with People First, which I am very pleased about (p.148)

Here Docherty appeared to be expressing a feeling of being an included and respected member of his community, rather than a prisoner of someone else's community.

Bersani (1998) suggested that social movements shared a number of characteristics that could be identified in the growth of the global self-advocacy movement. Some of these themes included the writing of its own history and raising consciousness. He went on to describe in detail how each theme was evidenced in the actions and developments of self-advocacy. The characteristics revealed that membership of groups needed to involve the sharing and acceptance of collective aims. However, Walmsley and Johnson (2003, p.179) regard these claims as 'adulatory and uncritical'. Equally it is precisely this sharing and acceptance of aims that has posed problems for People First in the UK to come to agreements on formulating a National organisation (Bright, 2000; Mack, 2001; Snell, 2002).

The position of some people within the social model is marginalised because there is a lack of focus on issues of access to knowledge and information and the understanding and taking on of a disabled identity. In terms of the situation of people with learning difficulties and the current theoretical debates, theory to support and guide the work of advocacy support-workers is confused and inadequate. The social model is not **quite** centring on the core needs and characteristics of people with learning difficulties. Furthermore, as mentioned earlier, they did not formulate, and were not involved in the formulation of the model from their own perspective.

How these theories affect the work of advocacy support-workers

What the principle of normalisation, SRV theory and the social model did, was lay out different perspectives for understanding the needs of people and the barriers they faced. There is current debate over just how inclusive the social model of disability is for the position of people with learning difficulties. The theories pointed to different ways of counteracting oppression in the life experiences of people and pointed to different ways of understanding the task of the advocacy support-worker role.

SRV theory and its links into identity theory, as developed in relation to people with learning difficulties, suggested a predominantly individual approach. People are assisted by others into valued social roles in order to change the perceptions and attitudes of the rest of society. This implied the advocacy support-worker and other supporters or advocates would have the knowledge and capability to make this happen.

The social model, in contrast, suggested that people acknowledging their oppression and forming a collective identity themselves could overcome oppression. Because the oppressor was society at large, people could identify particular barriers (law, access, benefits etc) and focus their efforts on what needed to change. In this scenario advocacy support-workers would be ‘allies’ or people who stood beside disabled people to help them achieve their aims, thus lessening the influence of the role of the advocacy support-worker. However the contradiction within the social model was that the very formation of a collective identity was hindered by the global approach to understanding disability. Some

sections of disabled people felt left out and excluded because they did not feel part of social model debates and direct action (Shakespeare and Watson, 2002b). Other disabled people, including people with learning difficulties, do not consciously know about the social model (Spedding et al, 2002).

Although these influential theoretical perspectives provide a useful insight and grounding to the work of advocacy support-workers, they do little to inform about the self-identified needs and aspirations of people, or how they perceive the world around them. Because of the lack of interest and investigation into the views and expectations of people with learning difficulties, support work to self-advocacy was theoretically left in a vacuum. Understanding the specific aim of self-advocacy, to speak out, was clear, but - in order to do exactly what?

More recent literature around identity provides a deeper insight into the multi-faceted nature of 'disability' and 'learning difficulty', and helps explain more clearly the various issues the advocacy support-worker is likely to encounter. It could be asked whether people with learning difficulties identify as a collective, and whether enabling this process should be the work of the supporter? Indeed it could be asked if supporters assumed that people **did have** a collective (ascribed) identity (Boer 2001), even if they, as individuals, were not espousing such a view. It is possible that advocacy support-workers adhere to a model of support without even being aware of it (Goodley 2000; Coles 2001). It is unclear from the sparse literature to date whether advocacy support-workers use a model of supporting in any consistent way at all.

It may not be the case that the role of the advocacy support-worker and what they do relies on a conscious theoretical base to work from. An unpublished study of self-advocacy support-workers in the North West of England which I conducted (Chapman, 1997), concluded that whilst some advocacy support-workers were consciously motivated and informed by particular theories, a number of workers were not theoretically orientated and just viewed their post as a 'job'.

Interestingly Coles (2001) noted, like Goodley (2000) that advocacy support-workers did not, for example, have to be consciously aware of the meaning of the 'social model of disability' informing praxis, to practise a social model of support. Therefore the need for a more empirically based study of the way support-workers perceive, and operationalise their roles, is clear.

2. The Task of Advocacy Support: How do workers learn about their role?

This section considers the theories discussed above in the light of how they influence the guidance and practice of advocacy support-workers. Two key questions are: what did the literature say on the role of the support-worker; and what is known of the perspective of group members, essentially the employers, about the support role?

In reviewing the literature, I grouped the guidance and studies into subject areas I felt were important toward the study. This was partly to reflect chronology and also to facilitate ease of discussion:

- Ownership and access
- Evolution of a supportive model
- Impact of social inequalities
- Relationship to professional standards
- The perspective of advocacy support-workers

Each of these will be addressed in turn.

Ownership and access

There are books and articles written by people with learning difficulties, despite the obstacles this obviously involves for individuals. Accessibility to the written word is, by definition, difficult for members of self-advocacy groups. In the main, the earliest (and continuing) examples of people's work are biographies and autobiographies detailing testimony of people's own life experiences (Bogdan and Taylor, 1976; Deacon, 1974; Hunt, 1967; Eardley, 2000; Townson (forthcoming). Advocacy support-workers may well be able to learn from people's past experiences, but the influence that may have on the job role has to be inferred by the reader as it is not explicit.

A related approach has been the co-writing of autobiographies and life histories, (Andrews with Rolph, 2000; Cooper, 1997; Tuttleby with Johnson, 2000). It is sometimes hard to tell just how much assistance has been given by the partner as it is not clearly defined (Walmsley, 2004b). However the main thrust of these publications has been to illustrate personal experiences. Atkinson and Williams' (1990) anthology, *Know Me As I Am*, was described as the first major publication to represent the authentic voices of people with learning difficulties (Walmsley

and Johnson, 2003). This work not only recorded life experiences, but also used a creative and imaginative approach to express different aspects and ideas of people's lives. However, although the material is useful background for orientation to the subject area, and one can perhaps make some assumptions about what is regarded as good and bad support work, it was not intended to be focussed towards the advocacy support-worker role.

Service evaluations undertaken by people with learning difficulties linked with professionals, was mentioned in Chapter Two, (*Our Plan for Planning*, by People First Liverpool and People First Manchester (1996) and *Oi! It's my Assessment*, by People First London (1993); Whittaker, Gardener and Kershaw, 1991). These evaluations had put forward ideas by people about what their services should be like, and therefore how service support may be oriented. But again, they were not about the advocacy role.

A more recent and developing approach has been the co-writing of articles to comment on current debates. Examples of these are about the issues people are tackling in their self-advocacy groups (Whittell, Ramcharan and members of People First Cardiff and the Vale, 1998); or the importance of education (Sutcliffe and West, 1998). Townson and Chapman (1999) also tackled issues around service consultation exercises and partnership working. Clark, Fry and Rodgers (1998) wrote about health issues for women and Downer and Ferns (1998) on self-advocacy by black people. Again recently, people with learning difficulties have become involved in research. This will be discussed in Chapter 4.

It is interesting to note that despite there being publications in partnership with, or by people with learning difficulties, none have so far focussed on the advocacy support-worker role, except for fleeting critical comment by Bright (2000).

Indeed the only writer to take an analytical perspective of the advocacy support role has been Aspis (2002). Her message is to urge supporters to take a broader view of their role and work with people around issues of power and social dominance, more akin to the social model perspective. There are, however, some implications; for example, the co-writer of articles has a role, which may be similar to the support-worker role. Walmsley and Johnson's (2003) analysis of the approach people have taken suggests this is often an 'invisible' role. Atkinson's work with Mabel Cooper (1997) is a case in point, where Cooper is the sole author, although Atkinson clearly took a major role in enabling the publication.

There are some accessible training packs about self-advocacy. A prime example is a video called *Start! How to set up and run a successful self-advocacy group* by Speak for Ourselves (1993). In Newcastle, Skills for People (no date) developed a pack *How to Plan and Run Courses that Really Help*. Also, an early pack developed by CMH, the LASA pack, (Values Into Action, 1988) is produced in larger than usual print with accompanying pictures, as is the pack devised for staff training about self-advocacy by Dawson and Palmer (1993) of East Midlands Further Education Committee (EMFEC). Even so, these were not packs designed by people with learning difficulties although it becomes clear that there have been long standing concerns over the importance of accessible information.

Material from the Norah Fry Research Centre, Bristol, in the *Plain Facts* Series (Townesley, 1998) and information put out by People First National (2003) and other self-advocacy groups (Self-Advocacy in Action, 2003), have explained how people can have more of a voice in services or discussions around policy. These materials are also intended to be accessible. Nevertheless, they appear to assume the undisputed and necessary role of a non-disabled support person (i.e. without the label of learning difficulty). By that I mean, the materials cannot be used independently if a person has access needs.

Townesley (1998, p.77) argued that ‘access to information in appropriate formats is a human rights issue’. Hence the continued use of any guidance that is not accessible to people conflicted with a very basic notion of what self-advocacy is. To follow Townesley’s view, information that is accessible is open to all. If it is not individually accessible then it could be suggested that it creates dependency on the advocacy support-worker (Chapman and McNulty, 2004). However, it is difficult to imagine how information could be accessible to all, especially people with profound and complex needs.

This polarisation takes us back to the issue of social identity discussed in the previous section. It was alluded to by Worrell (1988), an early writer on the advocacy support role from Canada:

The role of the advisor is to empower the powerless. (p.78.)

(my underline)

However Goodley (2000, p.132) had a different perspective:

...self-advocacy already exists prior to joining a group...
viewing self-advocacy as something that people with
learning difficulties need to be taught, may do a massive
disservice to the already existing resilience and self-advocacy.

In Goodley's formulation, people with learning difficulties were active and knowledgeable participants, with a wealth of experience to draw upon, not the passive learners implied by Worrell. Goodley's view suggested that members would better formulate guidance for advocacy support-workers. This would be based on the notion of the capacity of the individuals involved.

Thus most guidance and studies available for advocacy support-workers are written by people without the label of learning difficulty (Worrell, 1988; Williams and Shoults, 1982; Simons, 1992; Cone, 2001; Dowson and Whittaker, 1993; Whittell and Ramcharan 1998; Wilson 1997). If there is to be 'nothing about us without us' (Aspis, 2002) then the question has to be raised as to why the guidance and training packs would not be presented in such a way that group members could generate them and use them amongst themselves. The bulk of the guidance presupposes that the advocacy support-worker is necessary as a translator and facilitator and that the support-worker is unlikely to be a person with access needs regarding communication; indeed with a learning difficulty. Both of these presuppositions create dependency on the non-disabled support-worker.

In sum, most guidance appears to have been written by allies. Often (but not always), the guidance is not accessible. There is a tendency to build in dependency on support from non-disabled people. Moreover, people with learning difficulties have so far contributed little in print to the debate.

Evolution of a supportive model

In describing the way supporters should perform their role, some guidance is clearly influenced by normalisation and SRV ideas. For example Worrell (1988) mentioned ‘the wounds’ and the effects of labelling. Similarly Williams and Shoultz (1982) in talking about training resources commented:

CMHERA has organised several four- day in depth courses on normalisation...these courses would provide a useful basic orientation for potential advisors of self-advocacy (p.183)

Arguably during the 1980s, SRV and values-based training was seen as an ideal for advocacy supporters. *On a Short Leash*¹⁸ (no date), by Scotland People First, made a number of implicit references to normalisation and SRV, ‘feeling alien in the valued world’ and ‘having one’s life wasted’ (p3), as well as pointing to the necessity described by Wolfensberger of having a ‘valued’ person in support:

Many tasks and processes need a high level of problem solving and high levels of concentration. Support from a person who is both able in these respects and has had a life experience where these capacities have developed to a high degree is essential if People First Groups are to function in a way that is satisfying to the members. (p.6)

However, there was no empirical backdrop to this assertion and no evidence to indicate that the view came from the collective voice of people with learning difficulties. Accordingly this was an example of the assumptions that are made by non-disabled people about people with learning difficulties. In this case, a person with learning difficulties was not viewed as having the qualities mentioned by People First Scotland. In contrast, going back to the idea of capacity, Goodley

¹⁸ Note the title implies that it is the membership who holds power over the supporters.

(2003) suggested that people had a wealth of experiences and were indeed experts on their own lives:

Groups boast rich cultures that can instruct professionalism.
It would prove productive to respectfully draw on the experts
within the self-advocacy movement before trying to make sense
of support in the cosy haven of professional circles. (p157).

Again there are tensions and differences between the SRV theory about the position of people and that derived from a social model of disability. The social model assumed a role for people with learning difficulties in defining change for themselves, rather than being led by advocacy support-workers doing things for people.

Traditionally it was thought that different ‘types’ of support emerged from different ‘types’ of groups. Goodley (2001) presented a typology of the models of self-advocacy groups that run through a number of previous studies (Crawley, 1982; 1988; 1990; McKenna 1986; Simons, 1992; Dowson and Whittaker, 1993).

The four types were:

1. Independent and autonomous (such as People First and other independent groups)
2. Divisional, where self-advocacy groups emerge out of a larger organisation such as Mencap
3. Council, where they arise out of a larger group of disabled people
4. Service system, where groups take place within a service such as an Adult Training Centre. (p.16)

Groups that were service based, perhaps in Adult Training Centres and run by service employees were seen to be restricted by the ‘conflict of interest’ of working for the organisation (Worrell, 1988; Dowson and Whittaker, 1993; Sutcliffe and Simons, 1993). Conversely, groups that were independently set up and run by volunteers or workers employed by the membership were said to be supported in a more independent manner. However, Goodley (2001) rejected the notion of ‘good and bad’ typologies of support as he believed this view was simplistic and unhelpful.

On the contrary, Goodley found that support was fluid and open to change. More important than which ‘type’ of group a person supported was their own personal approach to support. He preferred a more complex analysis, plotting advisor interventions on a social model/ individual model continuum. He contended that this enabled us to capture styles and effects of support (p.202). Thus he analysed support interventions under a typology of:

- Advisor-centred versus self-advocacy-centred
- Deficit versus capacity
- Talking-over versus talking-with
- Expertise versus experience
- Missing the point versus addressing the point

In Goodley’s view, the type of support to aim for was self-advocacy centred. This implied it was based on a notion of capacity and working in partnership. It respected the value of people’s own experiences and addressed or focussed on the points raised by people themselves.

In addition he found that self-advocates were active participants who challenged and resisted advisors' interventions they felt were not appropriate or welcome, using humour to break down paternalistic communication. He also discovered that self-advocates offered each other immense support and encouraged one another. Like Wilson (1997), in his development of the notion of partnership, this questioned the idea of the advocacy support-worker/ member dichotomy as he attempted to redefine the relationship.

Modification can be seen in the changing name given to the advocacy support-worker. Initially it was the role of the advisor (Worrell, 1988; Dowson and Whittaker, 1993). People First Scotland (no date) refers to 'advisors and staff' and 'supporters and advisors'. People First Scotland separates advisors who are non-paid and supporters who are employed members of staff. Sutcliffe and Simons (1993) refer to 'support-workers' (p.74); 'advisors' (p.17); 'co-ordinators' (p.66); 'advocacy workers' (p.88) and 'advocacy development officers' (p.106). Initially, and according to O'Brien and Wolfensberger (1979), the role was to give support and advice. Now the advisor part of the role appears to be falling into disuse, replaced by a supporter role (who by implication does only what they are asked to do), which links more closely to the social model of disability. Sutcliffe and Simons (1993), talked about the **back seat** position and this is repeated by Goodley (2001). As time has gone on the expectation seems to have shifted towards a more background role for an advocacy support-worker enabling, rather than 'allowing', (Wilson, 1997) people to take more control. According to Wilson, (1997), 'allowing' is a concept resting on advocacy support-worker power.

Cone (2001) addressed the impact of change but in a different manner. She found, unsurprisingly, that training needs of supporters changed over time according to the developmental stages of the groups they worked in. She asserted that initially training needed to be around individual and internal issues with a later requirement for training on political and systems change. Another point made by Cone was that the groups were dynamic and therefore training needs were tied into what was happening for the group. Advisors responding in her study reported a preference for active training on the job rather than training that took them away from their work. She found that it was the young and new advisors who had more concerns about their broad knowledge base.

The limit of Cone's study was that only advisors were asked about their training needs rather than organisations and members. In contrast to Bright (2000) and Aspis (2002), Cone's study assumed again that only people who were not labelled as having learning difficulties would be employed as supporters.

In terms of the evolution of the model of an advocacy support-worker's role, the earlier literature suggested a great influence of normalisation and SRV theory. There was an assumption that people **wanted** 'valued' support as opposed to colleagues supporting each other. Goodley's (2000) analysis of typologies of support contested the traditional dichotomy of service-based equals 'bad', independent equals 'good' and looked more in-depth at the individual interactions within support work. His work moved the question of self-advocacy support onto a firmer link with the social model of disability. The changing terminology from advisor to supporter reflects this shift.

Impact of social inequalities

There is little analysis of the impact of social inequalities, other than those embedded in disability/impairment studies on the role of self-advocacy support. Moreover, Cone (2001) states that after reviewing the self-advocacy literature available she noted several weaknesses, one being that most published materials were not research-based but were simply descriptive accounts of people's experiences. Of the guidance and literature available there was little that makes any comment on any variables that may affect the relationship between the advocacy support-worker and those they supported within an advocacy group. Although uniquely, Goodley's (2000) study does take a critical-reflective research-based stance, and he looked at 'types' of group and 'advisor status', he did not specifically look at the advocacy support-worker identity.

Wolfensberger (1975) informed us that supporters should be people who are richly networked, with valued social roles, and this was amplified by People First Scotland (no date). Downer and Ferns (1998) state the need for Black advisors to Black self-advocacy groups, and Sutcliffe and Simons (1993) talk about the need for women's groups, groups for older people and groups that work with people with higher communication needs. However there is no evidence of a critical reflection about the role of the advocacy support-worker either in general, or according to his or her own identity. In the 500 questionnaires sent out to UK self-advocacy groups as part of Goodley's PhD (Bolton Institute, undated), where 134 completed responses were returned, there was no report of the findings around support-workers' identities. Yet it seems plausible that the age, gender or ethnic

origin of a worker (or indeed any other variables) may impact on their approach to the work and efficacy in the job role.

The lack of analysis of such variables is a general theme throughout discussion of self-advocacy in the UK today. There is equally a call for more focus on neglected minorities in the provision of advocacy as highlighted by the *Valuing People Taskforce* (2004, p.6):

Advocacy support needs to be available to ALL people with learning disabilities...not enough is happening for people with high support needs, people from ethnic minority communities and families.

As with the rest of the relevant literature, there is no cited evidence base for this position. An analysis of who advocacy is provided for, and by whom, is currently lacking and points to the need for a broader analysis of the role of advocacy support-workers.

Relationship to professional standards

Self-advocacy support roles appear to have developed in isolation from other types of professional role. There are many 'support' roles of people assisting in the lives of people who have learning difficulties, but none of them appear to specifically 'fit' the specialised role of the advocacy support-worker. Training of service staff may include information on people's rights and self-advocacy. However, writers such as Dowson and Whittaker, (1993) and Sutcliffe and Simons (1993) about the conflict between service and independent supporters, (amplified by independent self-advocacy and People First groups) have been highly influential. Most

services would claim to recognise the ‘conflict of interest’ barrier (Pochin, 2002) even if they did still engage in running groups with service staff as supporters. As the *Valuing People: Really Useful Guide* (2001) sets out:

Independent advocacy is very important and we agree that it should be available to everyone who needs it. (p16)

Support-workers in their other (than advocacy) guises may present as staff who go into people’s homes to give independent living support as well as in colleges and day centres. People themselves, under Direct Payment and Independent Living schemes also employ personal assistants (Askheim, 2003). The training of staff who are employed directly (or by organisations that are funded) by local authorities acting as support-workers in people’s homes is set by the *Valuing People* (2001) policy context and is required to be part of the Learning Difficulties Awards Framework (LDAF) training initiative. This means that new staff have to receive basic training within six months of taking up their post. At a minimum organisations have to offer the induction and foundation units which include areas such as, ‘what is learning disability, first aid, food hygiene, moving and handling, health and safety, challenging behaviour, abuse, communication’ (Cumbria Learning Disabilities Partnership, 2003). Likewise, care providers have a duty to ensure that their personal assistants are properly trained to at least NVQ Level 2 in Care. No obligatory training previously existed to instruct people to become personal assistants, a role very different from being carers. The Shaw Trust (2003, p.6) states:

What makes the personal assistant training different from traditional care courses is the focus is firmly based away from the traditional medical model of disability. The ideology is to promote independence by giving people the choice of who they want to employ and when,

thus enabling the disabled person to live a fully inclusive life not previously possible with traditional care support arrangements.

The modules for personal assistants reflect this difference. They include:

‘Disability Equality Training, Information on Direct Payments, Pain Management, Mental Health Awareness, Equality, Diversity and Rights.’ (Shaw Trust, 2003), and are less practical in content than those for more mainstream support-workers in day or residential care.

In contrast, Wilson (1997) attempts to put a (hitherto missing) framework around the position of the advocacy support-worker and ‘offer an insight into how they manage their work’ (p.4). For the purposes of his study he adopts a community development approach to empowerment, suggesting that community development worker training is the most apt and fitting for advocacy support-workers. The community development approach to empowerment divides power into the four categories of:

- Psychological – personal confidence, skills and knowledge
- Social - a diverse and tolerant culture
- Economic – reallocation of resources
- Political – access to decision-making structures.

(Harris, 1994).

Wilson believed that support-workers in advocacy could and should be working in this holistic and rounded way, tackling each aspect of influences on a person’s life. The difference in Wilson’s work is that he conducted research with self-advocacy group members to discover what their conception of the role of the advocacy support-worker should be, as well as researching with other advocacy supporters.

His findings are unlike other authors because he hears something different being said rather than the 'us and them' discourse that the earlier writers tended to refer to, and the assumption of all power in the supporter's hands:

One of the most important and interesting points to come out of the self-advocates outlook was the notion of working in partnership with the supporter, where neither the supporter nor the self advocate works completely independently or in isolation, rather a state of inter-dependence exists between both parties (p89).

He quotes one of the self-advocates, [The] 'self-advocacy movement needs supporters...we like supporters to work in partnership with us' (p.90). Wilson goes on to point out that working in partnership actually assumes less power over members:

Choosing when to intervene or not is a method of working which largely locates power with the supporter. Indeed 'letting' the self advocate work on their own is an approach which by its very nature places decision making and responsibility with the supporter. Whereas working in partnership is more subtle and multifarious, and a style of work which places a different set of demands on the supporter and self-advocate (p90).

Wilson's concept of partnership addresses the issues raised by Walmsley and Johnson (2003) about the subconscious influence of the normalisation idea on the work of advocacy support-workers. In his view the advocacy support-worker has a specific role that no one need be embarrassed to speak about or hide. Partnership like empowerment, cannot be given or handed out (Simons, 1998), it has to develop through agreement and the sharing of experiences.

Wilson (1997) argues that the community worker's background training is crucial to enable people to achieve change. He conceptualises support as a specific type of development work. He goes on to say that it is of vital importance that the role of the supporter is not determined by academic theory but by the best practice of **supporters** in the field **because** they are working in partnership with members. This is for the reason that if the role of support went straight from theory to practice it would lose the vital grass roots perspective it has, and ownership of the self-advocacy group members. As Townson (2002) observes:

In 1995 we had a difficult year for support issues. We found one of our workers did not believe in what we were trying to do and we had to deal with it. We learned a lot from this and we looked more closely at how we employed people and worked with them (p.10).

Partnership and intervention are important issues for advocacy support-workers; how far should they intervene or not with the process of what is going on in a group? Dowson (1990) had in mind more of a divide between advocacy support-workers and group members. He observed that there was much emphasis on 'the self-advocate being empowered at the expense of the support-worker' (p126), describing situations where advocacy support-workers were so intent not to be seen as 'taking over' that they stayed in the background to the point of 'total power shutdown'. This non-intervention and non-comment raises the question over the point of their presence if they had no role? The lack of training and formalisation of role is problematic to advocacy support-workers. Arguably, their performance cannot improve if no one is clear what they are actually there for.

In sum, there is a lack of clarity over the professional standards advocacy support-workers should espouse. Mainstream support training is not appropriate; personal assistant training is rather too individually focussed; the community development role may be a suitable model, but has not been widely adopted by name. Like Goodley (2001), Wilson has encouraged us to look at a broader role for the advocacy support-worker that links to ideas of capacity and the social model of disability in order to provide a way forward. Overall, the literature informs us that training, if it occurs, is ad-hoc, as there are no formalities, accreditation or specific guidance attached to the training of an advocacy support-worker. Further it has been ascertained from the literature that, in general, groups are not oriented to the idea of people with learning difficulties taking on a support function (People First Scotland, no date; Cone, 2001). Some self-advocacy groups have asserted the importance of creating links with other disabled people (Downer and Ferns, 1998) but this in itself does not question the assumption of the role for a non-disabled support person.

The perspective of advocacy support-workers

There is little information available from the perspective of the advocacy support-worker. There is emphasis throughout the literature on the 'backseat' position and how they are not to influence or take over from group membership. For example in an illustrated report from a Japanese study, Tsuda and Smith (2004) state:

A group is usually not going to be nice when advisors speak too much at the meeting (p.14)

And similarly:

The role of the advisor is not to take over or tell people what to do (Whittell et al, 1998, p.51).

They point out that training is invaluable as it gives an awareness of the issues, problems and conflicts that might be involved in learning how to provide support without the advisor taking over. However Ramcharan et al (1996) found that only a third of self-advocacy groups in Wales had people supporting them who had received training specific to self-advocacy. Significantly, Cone (2001) also shows that advisors have a high turn over rate and suffer from burnout. They also report that they feel they perform inadequately in their role (ie. their own self-evaluation).

This notion of silence culminates in the idea that the support role is transitory and the ideal position is not to be there at all. Dowson and Whittaker (1993) speculate that the end-state of good support would be that a group no longer required an advisor; as Worrell (1988, p.47) asks, 'Is it okay for self advocates to work me out of a job?' This notion does not consider the enduring role of 'supporter as ally' to the self-advocacy movement. Furthermore the idea that the advocacy support-workers work themselves out of a job (by empowering others) does not take into account the changing nature of group dynamics. New people may constantly come into the group, established members may move on, and advocacy support-worker expertise may grow through experience. As Goodley (2001, p.210) says 'further research could follow up the role of the non-disabled supporter in organisations of disabled people to see if rejection of support is hasty or acceptable'. This conflict continues within the guidance because alongside the idea that the advocacy support-worker should not (eventually) be there, is also the notion that issues of commitment and trust are crucially important (Worrell 1988). Dowson and Whittaker, (1993, p.20) take a similar view:

There is a whole range of skills and knowledge that would be useful, but the essential skill is a commitment to self-advocacy.

Yet showing commitment and building trust surely hinge on the idea of spending a long time in the role. Wilson's (1997) call for self-reflection and learning from the best practice of **supporters** in the field **because** they are working in partnership with members, is seemingly a voice in the wilderness. In scrutinising the literature, the silence of advocacy support-workers is not at all helpful in discovering more about the role or indeed what the gaps are in support and accessibility that need to be addressed. If supporters are silent, then other people and agencies are not going to be so clear about what they need to be doing to afford inclusion for people with learning difficulties, exacerbating problems of access and inclusion (Chapman and McNulty 2004). Furthermore, Tsuda and Smith (2004) argue that the apparent lack of conflict between supporters and members is because supporters do not state their opinions clearly. He adds that this way of role taking does not bring about a collaborative relationship. If supporters and members have no conflict, they do not develop.

The lack of evidence is apparent in the guidance. There is little more than opinion from writers about both supporters and people within their groups (Walmsley and Johnson, 2003). Because of the assumptions made throughout the literature as to what people with learning difficulties want and need, we are no closer to learning the truth without **actually finding this out** through grounded empirical study of people with learning difficulties and their advocacy support-workers.

Critique of the practice literature

If the literature reviewed is intended to effectively inform the advocacy support-worker about their job role, then it is a clear a lot of work still needs to be done. It is apparent there is little training and guidance available for advocacy support-workers of self-advocacy groups (Cone 1999, 2000, 2001; Ramcharan et al 1996; Sutcliffe and Simons 1993). There is even less based on empirical study, although in the UK Goodley (2000) is a notable exception. The guidance for advocacy support-workers is scant, more abundant in the 1980s than now, and at times contradictory. It does not, at its core, appear to value the role and expertise of the group members (Goodley, 2000), despite the notion that self-advocacy is about 'speaking out'. Hooks sums up this perspective, in writing on a related subject (1990, p.151), that there is:

no need to hear your voice when I can talk about you
better than you can speak about yourself.

The literature is descriptive, not evidence-based and generally acts as an orientation around values and the hazards of the role. As Walmsley (2004b, p.4) remarks:

...one of the drawbacks of lack of clarity over the role
people play...is that it makes provision of appropriate
training difficult, on both sides.

The literature shows there are no real suggested boundaries to the role, just ideas and assumptions of what the role should be about. Members, organisations and support-workers together do not identify the training of advocacy support-workers, if indeed there is any. Because there is no professional formalised training there are also no checks to ensure improvements are made, or to guard

against abuse. Further, it could be suggested that the assumption supporters will or should eventually leave groups devalues the importance of the role of the supporter engendering a feeling of being 'ill at ease', and undermines ideas of commitment and the role of the supporter as an enduring ally. The question around boundaries to the role appears to be of great (but understated) importance.

Similarly, when lists of the make-up of the support role are written out they tend to be contradictory, asking for a back seat position but at the same time for intervention (People First Scotland, no date), Sutcliffe and Simons (1993).

Likewise, Williams and Shoultz (1982) and Cone (2001), list several competencies that advisors should have. Again these conflict with the idea that the support role is to be in the background and non-interventionist (for example being a skilled trainer, developing action plans and writing for grants).

The guidance for advocacy support-workers in the field of self-advocacy appears to be based largely on normalisation and SRV theory, which highlights the role of support over and above the capacity and experience of group members. It also appears to be driven by values and redress rather than evidence-based (Walmsley, 2004b). In contrast, Goodley (2000) and Wilson (1997), take a different view. They begin to draw on empirical evidence and ideas from the social model of disability based on capacity, alliance and partnership.

Conclusion

In this chapter I have reviewed the literature around the main theoretical underpinnings of support work in the self-advocacy movement and then examined

empirical studies and guidance for advocacy support-workers in the light of these theories.

The theories of normalisation, SRV and the social model lay out different perspectives for understanding the needs and aspirations of people and the barriers they face. Despite the different theories suggesting different approaches for working with people in a support role, there are problems due to the lack of inclusion and voice of people with learning difficulties. They have been absent from formulating and stating their own views about the advocacy support role. Yet importantly there are fundamental issues to consider, such as the balance between rights and protection, the tensions between individuals and the group, the impact of individual impairment over societal barriers, identity formation and the problem of creating dependency. In view of the lack of information generated by people with learning difficulties, the nature and task of support work to self-advocacy is left unclear.

Similarly, in the review of the guidance for supporters within self-advocacy groups, a number of themes emerged which also required clarity. For example, the tension between the implicit idea that support-workers will always be required (and how current guidance backs that continuation) set against the conflicting idea that support-workers should work themselves out of a job. These pose dilemmas around levels of intervention pointing starkly at the lack of training and formalisation of the role. Again, until we have grounded evidence of the experience of support-workers and the perspective of their employers, we are not

in a position to comprehend what the role of the self-advocacy support-worker is or might/should be.

From the evidence of the literature it became apparent that research was needed on the role of advocacy support-workers. The best approach appeared to be through seeking the voice and experiences of people with learning difficulties and their advocacy support-workers. In this way it was hoped to shed light on this undefined but seemingly pivotal role.

CHAPTER 4

METHODOLOGY

The Development of Inclusive Learning Difficulty Research

From the review of literature, it became clear that the research needed to focus on empirical evidence from both support-workers and members of self-advocacy groups. The study required an analysis of the models and theories being used (or not) and an assessment as to what the role entailed. It also needed to look closely at the characteristics of advocacy support-workers and members, to evidence their perspectives of their own and each other's roles and identities. This would enable people to be clearer in defining the role – thus forming an evidence-base upon which to develop ideas around what the role was about and therefore what kind of training may be useful. However the main thrust of the research was to get behind the silence of the role and discover what was happening in self-advocacy support in the UK. From this basis, three main research questions were identified:

1. What are advocacy support-workers' perspectives of their role?
2. What are People First members' perspectives of the support-worker role?
3. What light does this shed on the purpose of self-advocacy groups?

This chapter aims to place the study within the methodological context that influenced the choice of methods of inquiry. The research needed to be inclusive and detailed for a number of reasons (see Chapter 9):

- Current government policy approach
- Development of academic knowledge around inclusive research
- Political and ethical approach towards research according to current disability theory
- The self-determination of Carlisle People First
- Importance of the insider perspective

Ultimately these research questions have neither been examined nor approached inclusively before. This particular study of support was both a product of the interest of the Research Group and myself and aimed to be inclusive from the beginning. Therefore the second focus of the thesis (see Chapter 9) was to examine the process and merits of an inclusive approach to research, which constitutes a fourth research question.

The first section of this chapter focuses on studies relevant to the development of inclusive learning difficulty research. These include early qualitative studies, (Goffman, 1963; Gouldner, 1973; Mercer, 1973; Whyte, 1943); the influence of feminism, (Gluck and Patai, 1991; Mies, 1983; Oakley, 1981); and participatory action research (Dash, 1999; Elliot, 1991; Stevens and Folchman, 1998). These have all been cited as the main foundations of the rise of disability research, which is the forerunner of inclusive research with and by people with learning difficulties (Ramrachan and Grant, 2004; Walmsley and Johnson, 2003; Wilson, 1997).

The second part of the chapter focuses on approaches to research, which have resulted from researchers taking on a commitment to social change (Towell and

Hollins, 2000). An analysis of the debate around participatory, (Cocks and Cochram, 1995; Chappell 2000; Mitchell, 1998) emancipatory (Barnes, 2003; Oliver, 1992; Zarb, 1992) and inclusive research (Walmsley, 2001), around disability and learning difficulty studies involves examining a number of issues.

A number of key methodological points are inter-dependent and intertwined throughout the chronology of the development of inclusive research. These include:

- the position of the non-disabled researcher in disability research (Aspis, 2002; Barnes, 1990)
- the research relationship (Atkinson, 2000; Barnes, 1990; Goodley, Armstrong et al, 2003);
- accessibility (Townesley, 1998)
- power and empowerment (Aspis, 2002; Beresford and Evans, 1999, Moore, Beazley and Maelzer, 1998)
- ethics of disability research (Aspis, 2002; Morton, 1999; Swain et al, 1998)
- validity, reliability and partisanship (Chappell, 2000; Hammersley, 2000)
- reflective awareness (Phillips and Blythe, 2000; Shakespeare et al, 1993).

As these issues are discussed they will be highlighted within the text. In practice they raise issues about evidence collection and its interpretation in inclusive research. These are outlined in the methods in Chapter 5 and because of the integrated nature of practice within inclusive research they are developed fully and reflected upon in Chapter 9.

The chapter finally examines the methods that have been constructed within inclusive research and identifies areas that might be further developed in the formulation of the methods for this particular study. A case for a multi-method approach is put forward.

A further consideration towards methods chosen for the study was to listen and react to the comments and ideas of the Research-team. The team had their own views of what might work for themselves, in uncovering information from their peers and workers. Chapter 5 goes on to trace the developments and discussions within the Research-team that led to the finer detail of the methods used and an in-depth discussion of the methodological issues as they arose in planning the actual research project.

1. The Background of Qualitative Research in the Field of Learning Difficulty Studies

Although a quantitative approach is useful for discovering a broad base of information about self-advocacy and has been used by Chapman, (1997); Cone, (2001); Goodley, (2000) and Tsuda and Smith, (2004), quantitative data can also act to conceal what is happening by brushing over the surface (Silverman, 2000). This particular research aimed to look deeper into the relationship between workers and members of self-advocacy groups and uncover the nuances and details of what happens within self-advocacy groups.

Qualitative research has developed a wide variety of methods aimed at revealing a deep understanding of social phenomena. Partly this can be traced to the

‘verstehen’ tradition (the German term for empathy) of Max Weber, the pioneering German sociologist. Weber (1964) argued that if social scientists were to understand the behaviours of individuals and groups then they must learn to put themselves into the place of the subject of enquiry in order to understand a view of their reality. In this study, it would imply looking at the perspective of support-workers and people with learning difficulties. Freire (1970) developed this perspective into his political teachings, arguing that radical social change could only come about through standing with people, fighting by their side, and living the same life. Freire is often cited as influential in the rise of research with and by oppressed people (Borland and Ramcharan, 1997; Kristiansen, 2000). Both Weber and Freire have to some extent been succeeded by post structuralist writers. This has the effect of giving prominence to voice at the expense of grand theory, a shift that is important to this research.

In this study it was essential to get inside the relationship between advocacy support-workers and members of groups to uncover what was happening between them, and how that influenced each person’s understanding of People First. I had a working background as an advocacy support-worker, and the Research-team were all members of People First. It was thought this would help to put us in the place of the subjects of enquiry, in effect two groups of people, advocacy support-workers and members.

However, this unique positioning also gave rise to other considerations around **role- blurring**, making the necessity for **reflexivity** of even more vital importance than would perhaps generally be the case: points I shall return to later.

There is no single agreed formulation of qualitative methods. These are based on many different approaches, influenced by particular perspectives of the social world.

Despite the range of differences within qualitative research, there are a number of commonalities as outlined by Hammersley (1992), and useful to this particular study, which include:

- An analysis of words and images rather than numbers
- Preference for naturally occurring data, observation and unstructured interviews
- Documenting the world from the view of the people studied
- A rejection of natural science as a model
- A preference for inductive hypotheses generating research rather than hypothesis testing.

From this starting point I began to look at research on and with people with learning difficulties.

Early qualitative studies in learning difficulty research

Twenty years ago Richards (1984) found that in the previous twenty years, only five studies had included people with learning difficulties as respondents (quoted in Walmsley and Johnson, 2003). Yet understanding meaning in everyday life is dependent upon a person's own perspective. It has taken many years of development to create research approaches that tap directly into the perspectives

of people with learning difficulties. What follows is a brief survey of qualitative methodologies that have been used with people with learning difficulties.

There were a number of early American qualitative studies about the lives of people who were oppressed such as those by Goffman (1963); Edgerton (1967); Mercer (1973) and Bogdan and Taylor, (1982). Even though these researchers were clearly concerned with how individuals made sense of their social world, there was a marked distance in the relationship between the researcher and the researched (Walmsley and Johnson, 2003). The methods used in these studies included participant observation, in-depth, unstructured or semi-structured interviewing and biographical and life history construction (Sidell, 1989).

The USA studies raised a question about whose standards people were being judged by, and who was doing the judging. Becker (1970) asked, 'Whose side are we on', implying that choices had to be made through being aware of the consequences of research studies (Gouldner 1973). Becker argued that there was no set category of people who deviated from the norms of society, but certain dominant and socially valued groups decided this at specific times and in different ways within different cultures. He therefore proposed researchers should be underdog partisans. However, Gouldner (1973) argued that the information provided to support the underdog was simply open to abuse by those in power. The theories around deviancy and labelling have been mentioned as part of the meta-theory of Social Role Valorisation in the previous chapter.

These debates, however, have been superseded by arguments about ‘voice’ within the post-structuralist paradigm. The loss of meta-theory has been replaced by the ‘validity’ of each voice. In this approach it is simply ‘voice’ that is important.

Other early work, in particular, Edgerton’s (1967) *The Cloak of Competence*, illustrated the damaging effects of other people’s views about people with learning difficulties. He described the efforts people made to resist and overcome those views by unravelling the latter’s own stories about their life experiences. His study followed 48 people who had left hospital for ‘vocational placements’ and were no longer under direct supervision.

Edgerton developed his methods by making sure no interviews took place before a relationship had been established between the researcher and the person. He used a ‘loosely structured’ schedule for the interviews and expanded this with comprehensive participant observation. In effect he used a **multi-method** approach aimed at uncovering detail whilst at the same time checking for **validity**. He went further and followed up the study both 10 and 20 years later providing a rare longitudinal perspective (see Simons, Booth and Booth, 1989).

A similar Scottish study (Cattermole, Jahoda and Markova, 1988) also used a combination of participant observation, and unstructured interviewing in a longitudinal study of people leaving institutions to settle in the community. It should be emphasised these studies were unusual as most research on people with learning difficulties is quantitative and focussed on impairment based issues (what people cannot do). This reflects the dominating influence of the medical model

and can be illustrated today by many of the current journals in the ‘learning disability’ field (see for example the Journal of Intellectual Disability Research and the Journal of Mental Deficiency Research).

Qualitative sociological work increased social awareness of the construction of negative social roles (Goffman, 1963; Edgerton, 1967; Mercer, 1973). Such studies provided valuable insights into societal oppression and domination, and the diminishing effects that it had on people’s lives. However, the studies were criticised for being insular and for not seeking wider structural explanations of oppression (for example see Gouldner, 1973; Stott, 1973 on Whyte’s 1943 study of Street Corner Society).

Observing social interactions and becoming **immersed** in the group or culture being studied can lead to a failure to recognise and explain the importance of wider historical, structural and political processes, in effect issues of **power** (Silverman, 2000). For example, within People First groups, if an advocacy support-worker’s interventions were viewed as oppressive, their actions could be attributed to their own personal shortcomings (see Spedding et al 2002). However it may be more useful to contextualise the advocacy support-worker in a wider societal framework of those who marginalise people and which has been influential in their own training process. This is what Goodley (2000) attempted to do in his study of advocacy support-worker interventions and what Aspis (1997) urges in her theorising around self-advocacy.

In addition, as discussed earlier, the place of ‘voice’ in the wake of post-structuralism has added another perspective.

Whilst qualitative studies offer different and richly detailed perspectives into the lives of people with learning difficulties, there are also problems of ‘othering’ (Nunkoosing, 2000 p.59). That is, of seeing the research subject as apart from oneself and one’s own experience (see also Walmsley and Johnson, 2003, p.127). For example, Williams (2002a) noted that Edgerton himself accepted societal norms in the way he spoke of his own expectations of the (limited) potential of people with learning difficulties. This is an issue challenged by the social model of disability (see for example Stacey Gramlich et al, 2000; Aspis, 2000; Carlisle People First Research-team, 2004). If the researcher is to enter into the field with a preconceived idea about the limitations of people, then they have a biased framework from which to draw their findings.

Of utmost importance in value-based disability research is the **relationship between the researcher and the researched** based on a notion of capacity and respect. As Atkinson and Williams (1990, p.241) pointed out, ‘the researcher has a personal impact on what happens’. Research that is based on ideas of the limitations of disabled people is also value-based. The point is to be explicit about the value-base of research, rather than postulating the notion of being value-free and therefore denying the issue exists.

The influence of feminism on qualitative learning difficulty research

In the 1970s and 1980s, feminist theorists, again concerned with **power** issues, influenced methodological approaches previously dominated by male academics (Bowles and Klein, 1983). Mies (1983, p.67), herself a feminist, wrote:

The methodological principle of a value-free, neutral, uninvolved approach, of an hierarchical, non reciprocal relationship between research subject and research object – certainly the decisive methodological postulate of positivist social science research, drives women scholars into a schizophrenic (sic) situation.

Wilson (1997) contended that feminist research, with its emphasis on the importance of establishing reciprocal relationships, was particularly useful in research with people with learning difficulties; the self-advocacy movement in particular highlights values such as equality and respect (Sutcliffe and Simons, 1993). Therefore it could be suggested that it is important to pay heed to issues of **power** between the researcher and the researched and acknowledge that most research relationships start from an unequal power base. This type of thinking has undoubtedly influenced inclusive learning disability research as shown below.

Oakley (1981) explained how she stayed in touch with women who had been part of her study and implied that in a reciprocal relationship there was no need to end the relationship just because the research ceased. However, this can be a double-sided issue. Closeness may create a more comfortable research relationship, but as Atkinson (2000) commented, ‘closeness can be exploitative’ and lead to dependency (Stacey 1991; Patai, 1991). Atkinson (2000) also described ‘Research as Social Work’ because it implied an unequal relationship whilst at the same time it required close contact. In building up a **close research relationship**, the

research started to resemble social work, in terms of the empathy and involvement required, as well as highlighting practical issues such as transport and money. Therefore there are issues to grapple with around the **relationship between the researcher and the researched** on a personal level, as well as on a general exploitative level (Moore et al 1998). Such discussion broadens into the realm of **ethics** because there is a question over creating dependency as a result of entering into the lives of people who are known to be socially isolated. It alerts the researcher that they have a **moral obligation** not to interfere needlessly and perhaps cause damage in people's lives (see Booth, 1998).

Oakley also questioned the issue of 'objectivity'. For Oakley, the sharing of oneself if wanting to elicit information from another woman was crucial to her study. It was paramount that women should be the researchers of women. It was suggested that men, defined as oppressors would be unlikely to understand the female perspective and therefore further oppress the women they studied, as again there was an evident power imbalance (Oakley, 1981). This concept, if applied to the study of advocacy support-workers and people with learning difficulties, would suggest that researchers who have been support-workers and researchers with learning difficulties were the best placed people to undertake research on their peers.

However, this particular argument is made more complex because, currently, people with learning difficulties are not provided with the opportunities to become trained academic researchers. There is also some scepticism as to how robust such research would be (Clement, 2002; Walmsley and Johnson, 2003).

In feminist methodology it was claimed that the traditional objectivity called for was in fact **subjective** in itself, because it was defined by a particular powerful group (men) and was therefore gender biased (Harding, 1987). Oakley, amongst other feminists, refined qualitative techniques so they were more 'person friendly' and understanding of different people's perspectives and needs, thus creating a less formal relationship between the researcher and researched (see Wilson 1997).

Feminist methodology has therefore been a strong influence in developing research approaches with people with learning difficulties. Shakespeare (1996), in discussing disability research, explains how he has been influenced by the feminist model of the research relationship:

Ann Oakley's work is important to me for several reasons. First, she departs from the traditional paradigm of 'objective' and 'positivist' social research and develops an altogether more equal and balanced style of interviewing (Oakley, 1993). Second, she combines her academic publications with more accessible versions of the same research, intended to be used by the type of women who form her sample (p.115).

This relationship implies the building of **trust**, similar to the ideas of Edgerton mentioned previously, about the necessity to 'get to know' the person.

There were also more enduring problems with feminist research that are of relevance to learning difficulty research. Feminism, like the social model of disability, neglected to focus on other variables between women, such as sexuality, class, ethnicity, education, and power (Downer and Walmsley, 1997; Walmsley and Johnson, 2003). Thus feminist researchers could still continue the oppression of groups of women through the decisions they made during the

research process (Gluck and Patai, 1991; Spelman, 1998), especially by ignoring wider differences between groups of women.

There are also many differences between individuals labelled as having a learning difficulty that need to be considered, not least issues around communication and comprehension of the research process. For example much work needs to be done to study if and how people with severe and complex needs could be fully involved as researchers. This raised questions such as, if self election could not take place then would the role be ultimately unethical? These issues are further flagged up discussed in Chapter 9, but it does need to be acknowledged that this study is about a group of people with learning difficulties already involved in the process of research.

In sum, learning difficulty research and qualitative design can learn from feminist debate, particularly around establishing reciprocal relationships, the sharing of oneself and a clear analysis of the objectivity/subjectivity debate. Davidson and Layder (1994) comment that whilst the feminist perspective of traditional social science research has given important insights, and helped strengthen the claim for qualitative research, it is questionable that there is as such a distinctive 'feminist research methodology'. However, it is worth noting that researchers can aim to be specific about what and whom each piece of research design is purporting to study, rather than just using a blanket term of 'women' or 'people with learning difficulties'. Certainly the methods required to include people in the research process are going to be varied depending on who they are. In other words there can be no set framework, but rather what Robson (2002) describes as 'flexible

design research' (p.167). Indeed, Simons, Booth and Booth, (1989, p.13), similarly contend that 'methodological eclecticism is a strength rather than a weakness', in this particular field of research.

The influence of Participatory Action Research on learning difficulty research

A further development towards inclusive research can be traced back to both Weber's notion of 'verstehen' and also Freire's (1970) ideas around action (see Heaney, 1995). This is the emergence of Participatory Action Research or PAR (Selener, 1997; Walmsley and Johnson, 2003). PAR visualises 'research-action', where members of the organisations studied participate in the process of research (Dash, 1999). Action research implies learning about organisations through trying to change them. It comes in many forms over a wide range of subject areas, including agricultural development, community development, educational reform and self-development (Dash, 1999).

In the field of learning difficulty it would imply further action towards the empowerment of people. The aim of PAR was described by Elliot (1991, p.49) as 'to improve practice rather than to produce knowledge'. In an early typology of the characteristics of action research he had set out:

- Action research seeks to explain what is going on
 - The explanation constitutes a story
 - The story captures the participant's point of view
 - The story is told in the common sense language people use
 - The story is validated by the participants
 - The validation involves unconstrained dialogue.
- (Elliot, 1978).

Action research therefore requires participation from the people it seeks to study which places it in a particular style of **ethical** framework (Rapoport, 1970).

Stevens and Folchman (1998, p.204) described:

At its best, the participatory action research experience empowers the participants in the research process, enhancing their sense that they are ‘author’-ities on their own lives and that their perspectives are valued and respected within and beyond their community.

It is interesting that although PAR implies further action towards empowerment, Stevens and Folchman (1998) state that it does not (necessarily) lead to further action but merely ‘creates a sense’ of further action.

PAR is also characterised by prioritising values and aims, not solely to describe the world but also to change it. Because of this it can be described as political, partisan and active (McClimens 1999). It values the fact that people within their own group have ‘local and expert knowledge’ (Dash, 1999, p.477). However, although it is an attractive option in disability research and helps counteract problems around exploitation (it can be useful to groups) and the relationship between the researcher and the researched (together they can act as partners), it is not regarded as an easy alternative:

Developing a critical rights based approach to disability research is an extremely demanding task involving the researcher in a serious critical engagement of their values, presuppositions and practices.

(Moore, Maelzer and Beazley, 1998 p.85)

This indicates that constant **reflective** questioning and criticism are an essential foundation of this type of research. That is, a continual awareness of where power

lies in the research relationship and who is affecting it. Ahern, (1999, p.408-10, quoted in Robson, 2002) suggests a number of points to consider using reflexivity to identify areas of potential researcher bias. These include being aware of your taken-for-granted assumptions and value base, identifying areas where there could be role conflict, recognising feelings that indicate a lack of neutrality and being open to recognising bias and addressing it. PAR, in the field of learning difficulty research is beset with complex problems to resolve about power issues within the research relationship, including the role of the non-disabled researcher.

In addition, there are criticisms about the very nature of PAR. Going back to the notion cited earlier by Elliot (1978), that the key enterprise of PAR is 'to improve practice rather than to produce knowledge', spurs Hammersley (1995, p.118) to urge caution and warn that, 'research should be value relevant without being designed to serve particular political causes'.

The issues of **validity and reliability** again rise to the fore because the researcher is regarded to be 'on a person's side', as a partisan and therefore not 'objective' in the traditional scientific sense. Validity is about the 'credibility' and 'trustworthiness' of a research study (Robson, 2002). On this topic, Chappell (2000) suggests that funding grants will be difficult for researchers to access if it is thought that **validity** is being compromised by unquestioning adherence to a movement's values. In other words, any show of political bias is likely to negate the giving of public funds.

The challenge for PAR then, is how to show **validity and reliability** whilst still aiming to fuel social change. According to Maxwell (1992), the main threats to validity in qualitative research are to be found in description, interpretation and theory. These can all be counteracted by being vigilant about how information is recorded and transcribed, being clear about how interpretations were reached and considering other alternative theoretical explanations. Clearly these aims are going to be harder to achieve when one is working with a group of people rather than as a lone researcher.

In sum to part one, the qualitative methodologies discussed so far have described the development of methods to help the researcher uncover meanings, including the reality of everyday life from the perspective of the research subject.

Immersion and time to establish relationships were clearly prerequisites to discover and reveal finer detail, whilst prolonged involvement could also potentially reduce threats to validity (Robson, 2002, p.174). Further refinements were suggested through the developments in feminist research, which again questioned traditional views of objectivity and called for a more **responsive relationship** between the researcher and the researched, and an acknowledgement of **difference** between individuals. Finally, PAR suggested an **ethical** framework involving partnership in research, where studies enhance **empowerment**, enabling social change for those taking part in research within their own organisations.

As Walmsley and Johnson (2003) comment, all these approaches have something in common - a commitment to social justice and change (also see Towell and Hollins, 2000). Furthermore, research studies based in a qualitative, ethical

framework often have similarities in terms of methods and probably share more commonalities than differences. In this study, some points of importance to inform the design of methods were likely to be:

- time invested in getting to know people (Edgerton, 1967; Atkinson and Williams, 1990)
- awareness of people's differences and individual needs (Gluck and Patai, 1991; Walmsley and Johnson, 2003)
- reciprocal relationships (Atkinson, 2000; Oakley, 1981)
- reflexivity over power issues (Clement, 2002; Morris, 1991; Wilson, 1997)
- benefits to self-advocacy and group members (Elliot, 1991; Stevens and Folchman, 1998).

The merits and benefits of 'multi-methods' (Simons, Booth and Booth, 1989), or 'flexible design research' (Robson, 2002), came to the fore as an appropriate framework. All of these ideas have been incorporated into the methodological approach, as described in detail in Chapter 5.

2. Focusing on Inclusive, Participatory and Emancipatory research in disability and learning difficulty studies

Like feminists and action researchers in their own fields, those working within disability studies have proclaimed that disabled people are the best authority on disabled people's lives. This was summed up in the popular slogan, 'nothing about us without us' (see Aspis 2000; Harrison et al, 2001). Participatory action

research, as discussed earlier, covered a whole range of approaches, enabling disabled people, (or people with learning difficulties) to take on a small, but significant, part in the research process alongside an ‘academic’ researcher (Chapman and McNulty, 2004). Participatory (action) research is where people work together and alliances are formed (Chappell 2000, p39).

Emancipatory research emphasised ownership and control of the research process (Oliver, 1997; Priestley, 1999, Zarb, 1992). Its history belonged squarely within the disability movement and the social model of disability. Ultimately the researcher could be called upon to put their skills at the disposal of the commissioning (disability) organisation. In addition to these approaches, Simone Aspis (1997 and 2000), has uniquely developed her own individual ideas as a researcher around the ethics of learning difficulty research as discussed later.

Walmsley, (2001) talked about the concept of ‘inclusive’ research, combining emancipatory and participatory approaches. She asserted that ideas around normalisation and SRV had influenced the role of the researcher in inclusive research. She contended that this often resulted in the researcher hiding the extent of their role in the research process, by emphasising the importance of people with learning difficulties within the relationships as co-researchers (because ‘researcher’ is a socially valued role), thus minimising their own impact.

Examples of this approach can be found within the autobiographical and biographical accounts in learning difficulty research – stories often supported by researchers as ‘sympathetic allies’ (Chappell, 2000; Walmsley and Johnson, 2003, p.66). In the past two decades many people’s voices have been enabled to reach

the public through the help of committed academic allies (Atkinson and Williams, 1990; Brechin and Walmsley, 1989; Goodley, 2000; Spedding et al, 2002; Traustadottir and Johnson, 2000).

Interestingly the efforts to reclaim the 'lost voices' of people with learning difficulties (Atkinson and Walmsley, 1999, p.204), have often resulted in the 'lost voice' of the researcher. Therefore it has been highlighted that there is a need to be explicit about the role of the researcher within whichever paradigm of research they are engaged (Chapman and McNulty 2004).

Walmsley (2001) classified both emancipatory and participatory approaches to research as inclusive research. However, the extent of inclusion (as opposed to tokenism and rejection) may be questioned. 'Inclusion' can involve people playing a limited or a major part in the research process and therefore clarification is needed, as recently suggested by the Carlisle People First Research-team (2004), partners in this research.

Emancipatory Research

Emancipatory research was a development of PAR, where research was to lead to social change in order to benefit disabled people. It has a developed set of criteria, primarily associated with the disabled people's movement, to explain what exactly makes it emancipatory (see Chappell 2000; Zarb, 1992). The British Council of Disabled People (www.bcodp.org.uk/about/research.shtml 2004) outline seven main principles, acknowledging that social research is a political process:

- **Control:** Disabled people must be involved from the beginning to the end of the research process. Non-disabled researchers can be involved but they must be accountable through the whole process to a committee of disabled people.
- **Accountability:** Accountability extends to all those involved in the research process. Procedures and practices must be open and explained to participants. The findings must be disseminated in appropriate accessible form to all those involved.
- **Empowerment:** The research must attempt to leave disabled people in a better position and not exploit their experiences for the career benefits of researchers. It should lead to meaningful, practical outcomes.
- **The Social Model of Disability:** The research should adhere to the social model of disability. It should focus on economic, environmental and cultural barriers encountered by disabled people and their families.
- **The need for rigour:** Researchers must ensure their methodology and data collection strategies are logical, rigorous and open to public and academic scrutiny.
- **The choice of methods:** The choice of methods must adequately reflect the needs of the project concerned and the wishes of disabled people.
- **The role of experience:** Discussions of disabled people's experiences, narratives and stories should be couched firmly within an environmental and cultural context in order to highlight the disabling consequences of a society that is increasingly organised around the needs of a mythical, affluent, non-disabled majority.

Oliver's paper in 1992, called for the social relations of research production to be overturned in calling for **emancipatory research**. This, he claimed, should be based on researchers putting themselves 'at the disposal of their research subjects, for them to use in whatever ways they choose' (p 111). Oliver went on to explain how, in his view, ownership of the research process by a non-disabled researcher simply extended oppression:

The persistent lack of fit between able-bodied and disabled people's own articulations of their own implications for...the ability of people to control their own lives. Oliver (1996)

Furthermore, the outcomes for the disabled person were of key importance in emancipatory research. Oliver, in similar fashion to the political commitment called for in PAR, urged that research around the lives of disabled people should:

...(be) both more relevant to the lives of disabled people and more influential in improving their circumstances. The two key fundamentals on which such an approach must be based are empowerment and reciprocity. (Oliver 1996, p.141)

Emancipatory research, based on the ideas of the social model of disability, has been the most pronounced approach in disability research studies. Chappell (2000), after reviewing the work of 'emancipatory' researchers such as Morris (1991), Oliver (1992) and Zarb (1992) claimed that emancipatory research should be commissioned by, and accountable to, democratic organisations of disabled people as well as providing opportunities for disabled people themselves to be researchers. Therefore emancipatory research both challenged the status quo and questioned the validity of research if it was not to help achieve the movement's

vision of a changed world. Accordingly, in answer to the traditional view of the necessity of ‘scientific’ **objectivity** in research, Barnes argued:

Researchers should be espousing commitment not value - freedom, engagement, not objectivity and solidarity, not independence....academics and researchers can only be with the oppressors or the oppressed.

Barnes, 1997, p110

However, despite the influence of the emancipatory paradigm, there were suggestions, particularly in the UK, that the position of people with learning difficulties had been marginalised in writings associated with the social model (Chappell, 1998; Goodley, 2004; Scott-Hill, 2002). Linked to this notion, Aspis, (writing in Campbell and Oliver, 1996) also claimed that people with learning difficulties had never been taken seriously inside the wider disability rights movement within the UK.

Walmsley and Johnson (2003, p.53) clearly defined the problems that people with learning difficulties encountered within emancipatory research as well as the commonalities they shared with disabled people. The main stumbling block was cited as **access**. Access is denied to many people through information not being made available in appropriate formats. This results in a lack of opportunities for researchers to go about their task because of barriers, not least in competing for appropriate funding. They concluded that, ‘For most research, people with learning difficulties need the assistance of non-disabled allies- and they are less amenable to control than technology’ (p.54).

Aspis (2002), called for her own eleven points on how to do research with people with learning difficulties. Her requirements are based around an inclusive, holistic approach to the research cycle, which concludes that people should be paid for their involvement in research. She stated:

People with learning difficulties must be involved throughout the whole process. This includes setting the project aims, selecting research methodology, designing the questionnaires, carrying out interviews with interviewees, analysing trends, drawing conclusions and making recommendations and decisions on what will and will not be included in the published report. Where appropriate people with learning difficulties must be supported to criticise previous models and theories and come up with their own. (p.17)

Similarly, People First National (2001) has written:

Researching...is something only people with learning difficulties can do...It is not right for someone without a learning difficulty to say what people with learning difficulties think about... they don't know what it is like to have a learning difficulty...It has to be us not a supporter or professional without a learning difficulty doing a degree – its our movement. People with learning difficulties and the self-advocacy movement has to become strong so that all the talk... can happen. **The process is as important as the outcome** (my highlight).¹⁹

The salient point in both of these statements is the emphasis on process, on **doing**. In emancipatory research it is quite acceptable for a non-disabled researcher to be undertaking a research role as long as the research process is controlled by an organisation of disabled people (see Priestley, 1999, for example). Because of this the Aspis (2002) and People First (2001) notion of research appears to be an **extension** of emancipatory research, illustrated by the addition that it should also be carried out **only** by people with learning difficulties.

Participatory Research

Participatory research in relation to disability and learning difficulty studies, is where people have taken part in the doing of the research in some way (perhaps as co-researchers), but the main organisation and ideas of the research is in the hands of an academic researcher. This approach appears to be used more frequently by people with learning difficulties and their allies than emancipatory research.

Chappell (2000) questions why this has happened. She discussed the issue around the social and material means of research production in reviewing the ‘emancipatory’ research studies examined earlier. Chappell concluded that researchers may be able to change the ‘social means of research production’ (working in partnerships with people who are defining and expressing the role of researcher within studies). However, the ‘material means of production’ are not so easy to address, (co-researchers being paid, the organisation of people with learning difficulties commissioning the research and attracting research funds). This points to the difficult problems around accountability and bureaucratic structures of organisations that need to be seen by others to be robust and secure, something difficult to achieve at times in the fragile learning difficulty sector.

However, there may also be more important points to consider about how few people with learning difficulties are involved in decision-making processes within funding bodies and organisations that commission research. This is an issue addressed by the National Learning Disability Strategy as explained by Towell and Hollins (2000), where there is a new vision of the ‘socially committed university’. The concept of representation and real inclusion through all layers of

¹⁹ People First National (2002) Private correspondence with author

the academy has yet to become a focal issue for academic institutions, though there are signs that this may be addressed.

Zarb (1992) contended that emancipatory research was not a real possibility until the social and material relations of production changed. Therefore, according to Zarb, the most one can expect until that point in time is **participatory research** - and suggests that participatory research may be a marker on the road to emancipatory research. However Chappell (2000, p.38) contested this position and made the point that:

The methodological conventions in social research into learning difficulties have institutionalised an important role for non-disabled academics in this field.

This is precisely the point that Aspis (2002) and People First National (2001) make. The position of people with learning difficulties in participatory research is usually based around the assumption of the non- labelled academic being at the core of the process, leading and defining the outcomes (Williams, 2002b). This implies that the power lies with the researcher.

A problem with **participation**, (as noted earlier about inclusion), is that it can be on a large or small scale and that each research project will define its own limits. Co-researchers with the label of learning difficulty may take part in that decision, or indeed it may rely on unspoken assumptions on the part of the academic researcher around competence (see Goodley, 2001). When, where and how participation starts and is negotiated can determine what conflicts may arise. For example, in *Good Times Bad Times* (Atkinson, McCarthy et al, 2000), women

with learning difficulties and academic writers prepared the text through a variety of different styles of collaboration. However it was noted that there were struggles in that collaboration that needed to be openly discussed. One of the main points that emerged in the explanation of the process of writing the book, was how the inclusion of women with learning difficulties as authors completely changed the process:

The arrival of women with learning difficulties in the group changed its focus and direction. There was no going back. The pace changed. Meetings needed to be inclusive and accessible, to involve everyone at a speed, and in a style that was respectful and empowering. This was an onerous task... (p.4)

Furthermore the explanation alerts us that conflicts indeed took place, 'We struggled with contradictory visions' (p.6). Similar to the comments of Aspis (2002) and People First National (2001), we learned that, 'The process of writing the book has been as important as the product' (p.5). This links back to Elliot's (1991) idea about PAR, that it was more important to improve practice than to produce knowledge. It is arguable that because people are so excluded by language (particularly the written word) unlike their physically disabled colleagues, the process of the doing of research has required such an emphasis.

Goodley (2000) also provided an informative example of such power relationships. Joyce Kershaw, in the telling of her story, objected to his editorial input and insisted on writing the piece herself, alone. This again is an example of the person taking power within the process pre-defined by the researcher. The fact there is conflict may be a positive point that extends learning. As Tsuda and Smith (2004, p. 12) commented: 'the lack of advisor/self advocate conflict may

point to a lack of opportunities for the two groups to recognise differences and to gain knowledge.'

Because of disparity in the relationship between the **researcher and the researched** it is very important to take heed of these **ethical** issues (Shakespeare et al 1993). Oliver's (1992) critique suggested that research should only take place if it is of benefit to the group of people it is about. Each time of asking for **consent or assent** (Sachs et al, 1994; Swain et al 1998; Walmsley, 1993) and of giving assurance of confidentiality (Morris, 1998), needs to be geared to the particular person who is the research subject. Each interaction requires taking into consideration the person's likelihood of initial understanding, or of how issues are to be addressed or repeated (Freedman, 2001). Obviously this has implications for this research project, a point discussed with the Research-team and developed in the following chapter.

Rolph (2000), for example in seeking consent, tackled the issue by using photographs whilst undertaking her PhD. This was instead of a written sheet to be signed by participants, to try and ensure there was a full understanding of her intentions with her 'Memory Group'. McCarthy (1998) and Morris (1991) pointed out that there is much 'behind the scenes' happening in the research process and that a one-off consent form is perhaps inappropriate, as different aspects of the research need to be reiterated and explained in different ways and at different times.

Relevant here to the methodological debate in learning difficulty research is to ask how much of the learning difficulty label is a social construction as opposed to an individual impairment. Deconstructing medical model notions of deficiency and inability and replacing them with social model concepts of capability, strength and the identification of barriers, suggests a political framework to question and analyse the historical generation of the concept of 'difference' (see Goodley 2000 p.36). Goodley maintains that many researchers now recognise the social nature of learning difficulties, particularly the label of 'mild' learning difficulties.

One of the major areas of difference in the learning difficulty field, (quite apart from age, gender, sexuality, race and class) are the huge cognitive and communication differences between individuals. Some people have multiple and complex communication needs yet others would easily 'pass' (see Edgerton 1967) as people without the label of learning difficulty, because of their skills, eloquence and confidence (Walmsley, in Gray and Jackson, 2002). Indeed, many of these skilled people are in the People First movement as leaders and have been prime subjects of biographical research (see Goodley, 2000, on interviewing 'top self-advocates' p.50). This is not to say that researchers have completely ignored people with high individual support needs. Walmsley and Johnson (2003p.127) do warn that 'people with high support needs who literally do not have a voice are excluded, unless other people with learning difficulties take up their cause'.

However, some researchers have. Atkinson and Williams (1990) were at pains to be inclusive of people with high support needs in *Know Me As I Am*, as were Grant, Ramcharan and McGrath (1993) by developing methods that could include

people with little speech through emphasising observational techniques (Walmsley and Johnson, 2003).

There are many examples of researchers working with people with learning difficulties in participatory studies (Whittaker, et al 1991; Ward and Simons, 1998). Further still, Mitchell, 1998; Rolph, 2000; Williams, 2002a have all attempted to develop inclusive methods in their PhD research. However, a number of writers have questioned whether people with learning difficulties can be included effectively in the whole research process (Clement, 2002; Kiernan, 1999; McClimens, 1999; Stalker, 1998; Walmsley, 1997; Ward and Trigler, 2001).

Many of these questions are indeed key issues unanswered to date. For example, in Paula Mitchell's study of 'Self-Advocacy and Families' (1998), the co-researchers with learning difficulties decided not to take part in interviewing because they did not feel comfortable about it (their decision) see March et al (1997). What we do not know is if Mitchell questioned their stance or challenged their view. We can only speculate as to whether co-researchers would have become more *empowered* by learning new skills or more disempowered by Mitchell questioning their expressed choice. These are issues that highlight 'process' (Aspis, 2000; People First National, 2001) and require careful consideration.

These points emphasise the complex role of the researcher who is supporting such research and inevitably questions whether the role of the researcher is merely to support co-researchers or to set the scene for empowerment and assist in

developing people's skills. Certainly, according to Ward (1997), other people have attributed to research the likelihood for empowering people involved. However, there is little acknowledgement of the learning and benefit to the academic researcher from the experience of working with co-researchers. In this sense, issues around research mirror some central dilemmas of the support-worker role.

Walmsley and Johnson (2003) maintain that self-advocacy has played an important role in enabling inclusive research to happen (p.54). Additionally the researcher might need to be immersed in the experience of the group (Freire, 1970). In order for the inclusive process to develop, it is arguable that people will need to be challenged into thinking in different ways to enhance confidence in people with learning difficulties as researchers and also to value the role of experience. In short, researchers with learning difficulties, like academics, would benefit from access to research training. In addition it is important that researchers self-select. There is little point in involving people in a tokenistic manner simply because they have a learning difficulty. Academic researchers in institutions are there because at some point in their lives they chose to take that path. One could argue this should equally be the case for any researcher.

Like Mitchell, Tsuda and Smith's (2004) study of Survey Research on Self-Advocacy Groups in Japan, reportedly included people with learning difficulties in reviewing the hypothesis and methodology of the project but 'did not extend further'. Tsuda and Smith commented:

It was regrettable that self-advocates were not afforded involvement in additional aspects of the research project.

Though their ideas were very helpful to the process, they were not comfortable discussing complex areas such as the hypothesis, methodology and concept of the research (p.8).

This quote actually informed us that this involvement didn't take place after all.

Unfortunately there was no further information on **why** people were not comfortable and **how accessible** the discussion was, or **how long** people had been involved or worked together, in learning about research skills.

Crucially then, Williams (2002b) commented about the research where she supported people with learning difficulties on the 'Finding Out' project:

...these researchers, like any others, should have access to proper training and support for their own skill development: any novice researcher requires some such induction, and self-advocate researchers are no different (p.9).

Other researchers claim there are particular parts of the research process that are 'too difficult', often that data analysis is the stumbling block for people with learning difficulties (Stalker, 1998; Ward and Trigler, 2001). As Minkes et al (1995, p97) explained in reporting on a participatory research project in Bristol:

We are aware that, to date, people with learning difficulties with whom we have worked have not been involved in every aspect of the research process. In particular, we have yet to develop an effective participative method of including people at the stage of data analysis, arguably the most complex part of the research process.

It may be asked that if people have not been involved in data analysis or attempted that part of the research at the outset, how do others (academics) **know** that it is going to be a stumbling block, other than by making assumptions.

In a broader manner, Clement (2002) felt that the call for inclusive research to be carried out in particular ways was unhelpful. He wrote:

If we accept that people with learning difficulties must really control the research process...then it means most research will come to a halt to train interested people with learning difficulties in research methods and methodology.

The reality is that people with learning difficulties are not knocking at the doors of academic institutions with pitchforks and torches (sic) demanding to do their own research (p.8)

Interestingly, Clement assumed research was based at academic institutions alone.

Whilst there may be truth in Clement's comment, he would perhaps have benefited from asking why people with learning difficulties have not made the demands that some other disabled people have. He does however posit an interesting critique of the disability research paradigm:

It was only on reading Hammersley (2002) that I began to see the disability research paradigm as an effort **to control** both who is doing this type of research and how it is to be done, rather than as a helpful guide for doing sound research..... (p19).
(My highlight)

In other words, Clement questioned whether 'control' of the research process by the disability research paradigm was right at all, as it excluded, through its rigorous demands, what he felt may be 'perfectly adequate' research by allies. Clement is likely to be criticised for asking these questions as a non-disabled academic, but it does raise a point about exclusion per se, of when and where and by whom it is acceptable or not. It points out that it is vital we hear that discussion from people themselves.

In consideration of the ideas of inclusion and control, Walmsley and Johnson (2003; p.64) defined the main aspects of what made up inclusive research, from their analysis of past studies, and the growing literature around participatory and emancipatory research. Their framework moved further forward than that of BCODP (see p.96) in regard to learning difficulties research, because it also considered the needs people had around information being made accessible and the possibilities for their inclusion as researchers. Because of this I have used their framework as a starting point for this particular piece of research. Each statement is further discussed in Chapter 5:

- The research problem must be one that is owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; non-disabled researchers should be on the side of people with disabilities.
- It should be collaborative; people with learning disabilities should be involved in the process of doing the research.
- People with learning disabilities should be able to exert some control over process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.

It is worth noting that it does not set out that initial ideas for research have to come from people themselves, and would thus differ from the view of Aspis (2000) and People First National (2001). This framework therefore leaves space for the notion of academics as allies. It accepts that research can (indeed should) be partisan and

that people with learning difficulties are required to be involved as researchers. The point about accessibility is clear, not just in providing information, but in the make up of the whole process of research. In essence the definition looks towards collaboration and partnership.

In sum, part two of this chapter has examined the methods that have been constructed within an inclusive research paradigm, specifically through disability and learning difficulty studies.

Because we know so little about the research that is wanted and required by people with learning difficulties, it is important to address the gaps that have emerged throughout the discussion. We do know that the **process** of research is viewed as very important (Atkinson et al 2000; Aspis, 2002; People First National, 2001).

Disability research, even where the research process is inclusive of people with learning difficulties as researchers, appears to be including people once the main ideas have been framed by others (Mitchell, 1998; Minkes et al, 1995; Townsley, 1995; Tsuda and Smith, 2004). The term 'inclusive research' does little to inform exactly to what extent inclusion takes place and where the main pitfalls are (Chapman and McNulty 2004). There is also little information about the role of the person with a learning difficulty as a researcher in terms of critical reflection (Walmsley, 2001), how much training of skills is available (Williams, 2002b) and how ideas get worked out between people. Therefore there is a need for

transparency and detail so that knowledge in this area can grow, and practice can be developed.

Although emancipatory research is called for by the disability movement (Oliver, 1992; Zarb, 1992), the aspect of controlling the funding is enormously difficult, given the general lack of inclusion of people with learning difficulties on formal bodies (Chappell 2000). There are further questions as to whether disabled people **should** be saying what is **wanted** in terms of research for (on behalf of) people with learning difficulties (Clement, 2002). This may simply lead to disabled people dictating about the needs of others and lead to another layer of oppression (Walmsley and Johnson 2003). Indeed this is an issue discussed later in the project (see Chapters 6 and 7).

Furthermore, the pervading issue of lack of accessibility in all its forms (Townsend, 1998) remains a huge barrier to inclusion. It may be suggested that if learning difficulty research was designed in such a way as to be accessible to individual people's requirements, then the whole process of research may lead to more control by people with learning difficulties.

Conclusion

In the light of this methodological review, I suggest it is important to work with people with learning difficulties to find their views of their own agenda for research. The research could be conducted by building on an individual's own strengths and ideas about what are the important issues to research, whilst developing methods that suit the abilities of the individual concerned. This

research therefore seeks to develop the practice of inclusive research by taking into account each person's individual requirements as researchers, whilst at the same time balancing the academic requirements of validity and reliability. I also conclude that although process is of vital importance (People First National, 2001), so is **production of knowledge**. I contend that it is not helpful to prioritise either one over the other but to attempt to balance the integrity of the two together.

I propose the definitions set by Walmsley and Johnson (2003) for a collaborative partnership approach to research whilst engaging in the use of a **multi-method** approach suggested by Simons, Booth and Booth, (1989) as fruitful starting points. Ideas that **parts** of the research cycle may be too difficult (Clement, 2002; Tsuda and Smith, 2004), appear to me to be rather sweeping and assume 'de facto' that people have the same (limited) abilities within the label, thus denying individuality.

The following chapter outlines the involvement of the Carlisle People First Research-team and illustrates how changes to the original definitions and framework of methodology, and ideas about methods, occurred through their interventions.

CHAPTER 5

METHODS

Developing Inclusive Learning Difficulty Research within the Research-team

A lot of researchers have complicated names for different types of research methods. What we want to do is use the methods that are available to us, not complicate it. When things get complicated it puts people off and then they feel rejected.

(Elizabeth Harkness, June 2004).



Introduction

This chapter outlines the actual methods used and adapted for the project, based within a qualitative paradigm. The study draws on previous knowledge, using inclusive research methodology, and was informed by Walmsley and Johnson's (2003) framework. The methods sought by the Research-team had to be both accessible and inclusive.²⁰

Developing the methodological approach within the Research-team involved trial and error and therefore took time. The process of supporting a team involved all

²⁰ It needs to be acknowledged that my role as a decision-maker within the team is likely to have been highly influential. I came to the group with knowledge and information, and had been teaching the group about research skills for a number of years before the project began (Chapman and McNulty, 2004).

the work being done at the level of each individual and what best suited individual preferences. The approach is bound to draw criticism from those who believe the process is not and cannot be open to people with learning difficulties because of impairment issues (see chapter 4). However it is my contention, and that of the team, that people genuinely interested in research can become more involved in ways that are individually appropriate.

The methods planned in this project seemed to be appropriate, in that they provided an ‘insider’ perspective, both for members of the People First groups and for supporters. In Chapter 4 I discussed the issue of partisanship and how reflexivity was vital at all stages; however the discussion is extended during this chapter.

What becomes clear throughout the chapter is that the supporter role and the researcher role are very different, despite having overlap and sometimes being described by people as one and the same thing. These issues are further discussed in Chapter 9.

This chapter begins with a discussion around the necessity for clarity of roles (Walmsley, 2004b) and an explanation of the different roles within the Research-team. This leads to a general outline of the methods agreed between the team for the study. At this point the chapter follows the chronological process of the development of the project, highlighting a number of issues which appeared to me as significant as main framework points indicating the research cycle. They have therefore been used as sub-headings. These include:

- Clarity of role- individual skills and agreements
- Deciding who to research and establishing an ethical approach
- Piloting the project – the importance of reflexivity
- Reflecting on research relationships – power and the Research-team
- Inclusive research methods in practice
- A case study of how the team prepared for work in the field
- Making data analysis inclusive.

I have endeavoured to be as open, transparent and detailed as possible about this process because of the previous ‘hidden’ nature of this type of support (Walmsley and Johnson 2003).

Clarity of roles – individual skills and agreements

Writing about this research project is complex because I have been involved in multiple roles as:

- having a prior working relationship with the Research-team
- a researcher
- a support and advisor to the Research-team
- a member of the Research-team
- a friend .

Chapter 1 described how the Research-team came to work together. It was explained that each individual’s involvement in this research was one of a number of projects the group had been involved in.

My role within the Research-team developed as a ‘bridge’ (to the academic world) and a translator (to make information accessible)²¹. I was a researcher and a facilitator at different times and within different phases of the project. My role of support to the Research-team involved teaching and informing as well as being a team member who learned from others. Overall I had a distinctive role, more akin to that of a team manager. Niall McNulty’s role as a supporter to the Research-team was more of a facilitative support role, rather than involving a teaching or managing role. Similar to the role of the advocacy supporter, it is important to be scrupulously clear about the role of the researcher. As Walmsley and Johnson (2003) observed:

Failure to define this clearly can lead either to the continuation of traditional research roles, in which the researcher continues, sometimes silently, to wield the real power, or a silencing of the researcher (p.82).

Although some of the project was about teamwork and taking on team roles, I also maintain that I had a clear role of researcher for myself. My research input was integral to the whole project. There were parts of the research undertaken that the Research-team have claimed as their own (Carlisle People First Research Group, 2002; 2004), but these were developed outside of this project, producing other outcomes and a clarity of ownership. The process of research, as indicated in the summary of the previous chapter, was **inclusive**, and aimed to work with people to find their own agenda for research, building on individual strengths and people’s ideas about the important issues.

²¹ See Chapman and McNulty, 2004, which describes in full the various roles undertaken within the Research-team.

As a Research-team, time was spent working through the ethics of an inclusive approach (Stalker; 1998, Williams 2002a), discussing how we could separate our various pieces of work to enable ownership at a number of levels (Research Planning Group Review 15th October 2001). This was to fit the first definition of inclusive research as described by Walmsley and Johnson (2003 p.64):

The research problem must be one that is owned (not necessarily initiated) by disabled people.

In effect we negotiated the issues of inclusion and support. I assisted the group to do parts of the research they wanted for themselves, and the team became involved in this project as researchers. This resulted in two separate strands of work that initially began as part of the same project:

- The role of advocacy support-workers as reported in this thesis.
- Research on the History of People First groups, undertaken in the Group's name and recorded elsewhere.

This suggests the project was complex in its nature. However there are precedents within inclusive research of co-researching particularly in terms of undertaking PhDs, which have informed the development of this project (Mitchell, 1997; Rolph, 2000; Williams, 2002a). This was mentioned in the last chapter and is a discussion returned to in Chapter 9.

Learning skills of research and people's own interests

The group learned about research skills together before the start and throughout the course of this project. This occurred from the beginning of the research process, the development of ideas for projects, through to fieldwork, analysis, plans for presentation, dissemination and evaluation of the final project. This fitted the third definition of inclusive research by Walmsley and Johnson (2003, p.64):

It should be collaborative – people with learning disabilities should be involved in the process of doing the research.

An article about this process was written by the Carlisle People First Research Group (2001b) and published in Community Living magazine. The article described the process and stages of a piece of planned research (a History Workshop) and how inclusion was important all the way through each stage. The main stages referred to started at planning together; learning about other work; meeting people and undertaking relevant work; undertaking the research (fieldwork); analysing the information; writing it up in an accessible way; making training packs; letting others know about the research and reviewing the process. Research group (RG) planning meetings were also minuted to provide a record of the first year of this project, recording how the team worked together and what was discussed.

As outlined earlier, the team had met and worked together before the onset of this particular project. A crucial point was that as a researcher I was familiar with the people I was working with and likewise they knew me. We were involved in each

other's lives in reciprocal relationships (Atkinson, 2000; Oakley, 1981, Wilson, 1997), and had already been engaged in a number of pieces of work together. I did not have to begin from the beginning in learning about people's skills as we were all aware at the beginning of the project of each other's skills and needs. The plan to work as a team was to make the most of people's individual skills and complement each other's expertise. The focus on each person's needs and interests meant that the work had to be organised in a way that was accessible to the team. The initial learning was not presented in a didactic manner but in a naturalistic manner when the opportunity arose:

In our first year of sessions the support I gave was fairly intense as through our discussions I passed over what I knew about the research process and research skills. This was not attempted in any formal sense as we followed where the discussions went to about people's own lives and the things they felt were important. When I could I would try and notice the spaces to bring in some teaching points. In time people in the group became interested in some of the ideas that were overlaid with jargon and we started to unpick these.

Chapman and McNulty (2004, p.79)

An example of how people's own ideas and interests affected project decisions can be taken from the early part of the project. Lou, as a team member, was particularly interested in the 'jargon' word, 'hypotheses'. The discussion in the group about this concept led the team to discuss projects they felt were necessary to do, and which they have gone on to do (see chapter 9).

This joint approach was illustrated well throughout my own project. My particular interest was in the role of support-workers in the advocacy movement. I had left my post at People First to take up a studentship at the Open University:

I had applied to the OU with ideas for the proposal that were essentially mine, although they had of course emerged out of working as an advocacy development worker for People First...the moment I knew I had a place at the OU I told the group and we discussed it at our meeting. At this early stage Andy, Lou, Malc and Elizabeth said they wanted to be involved. We spoke about the idea of participatory research.

(Research Journal (RJ), August, 2000).

Later,

Andy suggested calling our group the Research Planning Group as it was about a new project.

(RG meeting notes: October 2000).

This type of input followed the fourth definition of inclusive research by Walmsley and Johnson, (2003, p.64):

People with learning disabilities should be able to exert some control over process and outcomes.

In sum, the team members brought to the group their own interests and ideas about what would make a suitable and useful research project, and in the case of this project brought their experiences to shape it. The team decided early on, recorded in a mission statement, that any work undertaken was to be of benefit to the self-advocacy movement. This fitted the second definition of inclusive research by Walmsley and Johnson (2003, p.64):

It should further the interests of disabled people; non-disabled researchers should be on the side of people with disabilities.

This thesis then, explores the development of one particular project, but at the same time reflects on the development of an inclusive Research-team working on several projects.

Agreements over methods in the team

To return briefly to the research question, the project's main aim was to investigate the role of the advocacy support-worker. This question flagged up the need to discover the meaning of self-advocacy from members and workers and therefore the purpose of the groups. It was thought that understanding these meanings would uncover what it was that advocacy support-workers did and why. It was also important to find out if what they did was helpful towards members' understandings of self-advocacy, or conversely, acted as a barrier of any kind? This led to questions about power, knowledge and information, values, trust and relationships (see Walmsley and Johnson, 2003).

The process of research was intended to be as participative and accessible as possible, drawing on the Research-team members' abilities, experiences and strengths. As there was no real 'tradition' in itself for this kind of developing research, the methods used within the project were qualitative but purposefully eclectic as described in the previous chapter, (Simons, Booth and Booth, 1989). A flexible approach was used to situate the research in the everyday life experiences

of the participants, and to seek perspectives, meanings and interpretations of both advocacy support-workers and members (Goodley, 2000).

The task was to get behind rhetoric to 'real' meaning, (Gubrium and Holstein, 1997) implying that interviews and observations were of paramount importance. The workers were questioned about the views and opinions they held and then observed to see whether the views expressed in interviews were translated into actions (Barnes, 1997).

One point of triangulation was to discover if group members perceived the views and actions of advocacy support-workers in the same way. Triangulation (Denzin, 1988) is where more than one theory, method, researcher or approach to analysis is involved in order to improve the validity of the research. Our approach focussed on different research contexts within a People First organisation, such as a variety of meetings, groupwork, interactions, everyday conversations, observations and interviews. This settled the research in the everyday context and reality of concerns of the participants and, more vitally, it respected the right of participants to define their own experience vis-à-vis the social model of disability (Oliver, 1996).

A further check for validity was through tracking the conceptual background and process of production of job descriptions, business plans, contracts, policy statements and other formal documentation relating to the organisation. It was assumed (but held to later scrutiny) that the values and aims of the organisation would be reflected in the written word.

The Research-team discussed the different qualitative methods cited in the previous chapter and chose to add their own preferred methods of using photographs and working in groups to elicit information. Each research venue was photographed alongside activities the groups undertook. This was to provide additional visual data for the analysis stage, to act as an aide memoir, and for use in later accessible reports. Some of the team found it impossible to read documentation for themselves. It was important to try and counteract this so as not to create dependency on research support to translate and, in doing so, possibly interpret what was written about the organisation.

Whilst it is apparent that photographing in itself relies on some level of selection and interpretation as to what scene or action is photographed and why, it was felt that photography tended to limit secondary interpretation. In addition one of the team members, Malc, was keen on taking the photographs himself. Andy, in particular, felt photography was going to be useful to the study, saying, 'the camera never lies'. He brought this topic up because he was fed up of 'not being believed' by his home carer (RG meeting notes: November 9th 2000). The point was that the input of team members in planning the project drew on their personal experiences, particularly events that were happening at the time that made a cogent link, and as such were brought up naturally in conversation.

The groupwork method (Walmsley, 1990), was also of particular significance to members because of its familiarity. It emulated the typical process of the way self-advocacy groups operate. As Lloyd Page remarks in Goodley (2000):

Being in a group helps you to speak out. By speaking to people in the group it gives you the confidence to speak to other people. Sharing ideas you can get more out (p.84)

The members of the Research-team felt that by working in groups, people helped and assisted each other, with the more vocal assisting quieter people to have a voice. This again drew on experience from their own self-advocacy group, where support and interdependence, along with role-modelling, played a significant part. In contrast, it was also discussed that the validity of group responses can be questioned, as some people may lead others or themselves bow to group pressure (Alderson, 1995; Brown, 1999; Hoppe, 1995; Robinson, 1999). The group therefore talked at length about reflection and the necessity to look critically at the ideas we had.

In the Research Planning Group, Elizabeth guided the discussion, taking on the role of teacher:

If you want to find out...you need to look into how you do it. Methods is how you look into things. Types of methods are, asking questions, making programmes and videos, getting information from books, asking questions of different people, visual contact and listening. We should talk about not going over the heads of people- people's privacy and people from ethnic minorities. We need to understand their language. Everyone should be included. (RG meeting notes: 2nd March 2001)

The methods used were therefore purposefully eclectic and **accessible** and incorporated some facets of action research too, such as being participative, qualitative and reflective (Elliot, 1991). A main point was that the methods lent themselves to participation, and the development of a team approach, as well as trying, at the outset, to ensure that participants felt comfortable and respected. It is

interesting to note Elizabeth's very natural approach to the ethics of inclusion. The emphasis on accessibility met the fifth definition of inclusive research by Walmsley and Johnson (2003, p.64):

The research question, process and reports must be accessible to people with learning disabilities.

The next section gives a chronological account of the process of getting into the field. It refers back to notes from my research journal, and relevant reports from the Research Planning Group (see Silverman, 2000).

Deciding who to research and establishing an ethical approach

It was felt important to research self-advocacy groups that had been running for a number of years (ten years or more), so that advocacy support-workers and members would have a depth of experience and view of the group's development. This would help to answer the main research questions:

1. What are advocacy support-workers' perspectives of their role?
2. What are People First members' perspectives of the support-worker role?
3. What light does this shed on the purpose of self-advocacy groups?

There are over 1200 self-advocacy type organisations in the UK (Carlisle People First Research Team, 2004). In the role of lead researcher, I suggested that we looked specifically at groups that referred to themselves as ‘People First’, which brought with it a set of assumptions around independence and user-led ideas that could be tested. They were essentially groups that (in theory) were not going to be attached to services, and therefore possibly more grassroots oriented. It also seemed important for the research to reflect development and diversity in the four countries of the UK. Part of the third question was likely to touch on why it had been so difficult, over the past twenty years, for the groups to set up an effective national organisation. We talked about this in the Planning Group:

Elizabeth: It would be good if we could all unite and put it to the government.

Rohhss: Do you think everyone in People First groups know what National People First means?

Malc: We need to tell the people in Carlisle. Not everyone knows.

Rohhss: We could come unstuck here. When we go round asking people what they think about National People First, some people won't know what we are talking about. A bit like when we went to do that research at the ATC [Adult Training Centre] on consultation, and no-one had told people they were moving out...Do you remember what happened?

Andy: They didn't have the faintest idea about it.

Rohhss: How did we get round the problem?

Louise: We had to stop and get the manager to talk to everyone about it and then go back and ask them what they thought...when they knew!

The issue for the Research-team was whether we should be informing people.

Were we the ones to tell people about national issues or, as researchers, should we just go and find out what people already knew? The discussion dwelt on whether there was a moral obligation to inform as well as research, as put forward by Elizabeth and Andy:

Elizabeth: We need to give them a wake-up call!

Andy: Of course we should tell people, it's about their movement!

These discussions prepared us for what might happen in the field. In academic terms we were debating the possibility of praxis, where the end result empowers every individual involved (Erlandson, 1993, cited in Goodley, 2000 p.59).

We had to limit the number of People First groups to research. The intention was to study six groups across the UK that had been running for ten years or more, that had a variety of funding sources, for comparison and focussed on a number of core issues. This was based on the idea that if a group had been running for ten years or more then there would have been many experiences for people to reflect on.

We would perhaps come to understand whether the advocacy support-workers or the members were influencing the focus of issues within groups, and of trying to draw meaningful comparisons between groups which were in some key respects similar. The groups would also have been running long enough for people to have encountered a diversity of opportunities or problems and where changes might have occurred. Six groups were not many, considering the number of groups in the UK, but because the study was qualitative in design and to be focused on the

process of inclusive research, it was felt this would provide enough data for the purpose of the study.

Explaining the research to others

The process of choosing the groups was narrowed down by the above requirements and then discussed at the Research-team meeting, whilst referring to a large map. It was important to ground information back to something visual, graphic and real rather than continually try and deal with the abstract (see Simons, Booth and Booth, 1989). Due to lack of resources, the idea of going to Northern Ireland was initially dismissed and the national spread restricted to Great Britain, represented by Scotland and Wales with four groups chosen in different areas of England. Because it was a small sample we looked for geographical spread.

Once the groups were chosen they were sent **accessible** and illustrated letters with photographs of the Research-team, which explained the broad purpose of the research and asked the group for permission (see Appendix 3).

The letter for permission was broad in content and did not directly explain that the study was to look at the relationship between members and advocacy support-workers, but rather that the team would like to come and see how their group worked. This would, of course, include looking at relationships within groups. However, not being too overt essentially avoided issues of defensiveness or oversensitivity to us when we arrived. There had been debate by the team around the idea that a true picture of groups and their relationships could only be obtained by feigning to enter the group as a member, or becoming employed as an advocacy

support-worker, that is, covert, or ‘undercover’ research. There was much interest in this because of the group’s recent experience of watching and discussing undercover television reports of abuse in care homes. Although these ideas stimulated interesting discussion and speculation, in the context of this study they were eventually dismissed as being unethical.

Obtaining permission

There were difficulties in obtaining consent from two of the initially selected groups of choice. The first group refused because they felt it was unethical for a person without the label of learning difficulty to be involved in any sort of research about a People First group. After many months, they eventually sent a letter articulating this view (see Chapter 4). This links back to the complications of the role of the non-disabled researcher in disability research (Aspis 2000).

This particular group wrote and complained to the Department of Health about this research project, making inaccurate assumptions about my role. This is an example of the emotive politics of learning difficulty research. The process was enlightening because it emerged that an advocacy support-worker led the incident. They had not known of the details relating to the research, or indeed that the research had nothing to do with the Department of Health. In essence, and with the help of my supervisors, we were able to acknowledge and learn from it, after overcoming the initial reactions of disappointment and frustration.

The second group refusal was also enlightening. Three members of this group had told me informally that they were very keen for me to come to their group and for

the research to begin. However during a prior visit, an advocacy support-worker questioned me intensely about the project plan. Eventually I received an e-mail to say the group had decided not to assist with the project, with no further explanation. Elizabeth, who was very keen on researching that particular group, was upset by this response and wrote twice to the group to ask why. No response was ever supplied. In this instance, part of the research support role was to assist people to deal with feelings of rejection.

Thus two groups refused to take part in the research but on both occasions the refusal appeared to be influenced by advocacy support-workers, who were acting as gatekeepers to the groups (Hammersley and Atkinson, 1983). This suggested there was a gap between the knowledge of the advocacy support-worker on issues of inclusive research, and the knowledge of group members. By this I mean that members were welcoming to the idea of being researched, but workers clearly had other issues to think about that affected the decision making of the group.

The other four groups (A, B, C and D) were welcoming, although group A asked for more details and wanted further assurance as to the confidentiality aspect of the research, which was supplied.

The team still wanted to have six groups to study and later made contact with a People First group in Northern Ireland that fitted the criteria. This was through Malc meeting them at a National People First conference:

Malc: We met Ireland at the national AGM and they have invited us over!

Elizabeth: England People First would be a good idea, including Northern Ireland, Wales and Scotland. UK People First would be good.

(RG meeting notes: January 12th 2001).

This group (E) was then approached in the same manner and invited the team to visit.

Due to changes that happened within the process of fieldwork, a sixth group was never sought. The five groups covered the four countries of the UK, with two groups in England being based at either end of the country. As it was not a quantitative study and we would always need to be limited in the claims we could make for People First groups in general, it was felt there was likely to be enough data available to gain a feeling and impression of People First groups.

Three of the group's main supporters were men and two of the group's main supporters were women. Unfortunately there was no representation of supporters from ethnic minorities, which would have widened the scope of the study.

However there would have been problematic issues to address around my personal suitability to conduct research that involved participants from ethnic minorities, similar to the debate posed by feminist researchers (Downer and Ferns, 1998; Gluck and Patai, 1991; Spelman, 1998).

The role of the non-disabled researcher

The letter of complaint from the first group proved to have a great impact on the Research-team. There was an initial stage of anger and disappointment: 'Lou said

she was very annoyed about this and muttered a swear word under her breath...' (RG meeting notes: 2nd February 2001). After this subsided the issues were discussed and changes were made in our approach, resulting in the eventual split of the research into two strands. It took a while for the ideas to develop within the group, for all of us:

Malc: I say we are quite happy with what we get – our facilitator, we are teaching each other.

Andy: Well I think they are interfering too much, I do. I'm sorry to say this Malc.

Rohhss: Do you think there may be an issue here? They can't dictate what we do as a group, and as long as everyone is happy, well that's fine. But they do make some good points...

Lou: But the way they went off and wrote that letter! Why couldn't they have checked the facts first?

Rohhss: They made an assumption I was working for the Department of Health. I have offered to go and explain but they don't seem to want that.

Lou: Well what the hell do they want then?

Rohhss: We maybe need to separate the complaint from the research. Should a researcher without the label of learning difficulty be researching anything to do with People First? They are saying, no, they shouldn't. It's fine for the Research-team to do it as they share that label, like it or not....

...I could back out of the research. If you guys were doing the research you could carry on without me, then it would be totally owned by people labelled as having learning difficulties.

Andy: I think we would need support along the way.

Lou: Yes, I think we would.

Rohhss: Could the support person have a learning difficulty or not?

Andy: No. It would be you or Jozi or David (other advocacy support-workers without the label of learning difficulty).

Rohhss: You say it could be me. What is the difference then?

Malc: We are all the same and we are all people. We are all equal people.

Rohhss: So you see equality within the group?

Andy: It doesn't matter who they are...

Malc: We are all classed as normal people.

Lou: I don't like that word 'normal' Malc.

(RG meeting notes: Feb 2nd 2001)

Later the discussion shifted to whether advocacy support-workers were necessary in advocacy groups in general. What was not said was whether the research supporter should have any expert knowledge to put at the disposal of the group (Oliver, 1996).

Andy: What would it be like Rohhss if we asked you not to come?

Rohhss: It would be fine. You would be taking power for yourselves.

Lou: That's a thing isn't it!

Rohhss: It seems to be something you really need to think about. Maybe they have made some interesting points? (RG meeting notes: Feb 2nd 2001)

This illustrates the complexities of power issues in the team. I had actually framed the suggestion that the team might want to go on without me, and then reinforced the idea with the team that it would be their taking power.

Following this discussion the Research-team met without support. I was concerned regarding how to support the group effectively from an absent position. I did not want to lead the process (although I evidently had) or leave people ‘high and dry’. It seemed crucial to step back and enable the process to develop in whatever way it did, to see what emerged, in the same way the project itself was to find what emerged about the role of the advocacy support-worker. It was like a mirror.

The minutes for the next meeting were scant:

*This meeting was held at Andy's house and was to be the first meeting without support. Malc and Elizabeth did not turn up. Andy and Lou decided not to talk about the issues as there were not enough people there.
(RG meeting notes: Feb 16th 2001)*

By the end of February the group were all meeting together again. Item 10 on the meeting notes of February 23rd 2001 records, ‘*We talked about the idea of separating talk with people labelled as having learning difficulties from talk with support-workers.*’ In retrospect this was the building block from which the separation of the People First History Project later emerged. At this point the team

acknowledged a need for support, but wanted to claim ownership of the research cycle for themselves.

So, interestingly even the process of obtaining permission from groups impacted in a dynamic way on the approach of the Research-team, a kind of inverse action research, where the other groups raised points of a debate that had not been previously considered by the group. This testifies to the importance of considering learning from all stages and aspects of research, highlighting that gaining access is a very important stage.

Consent

Robson (2002, p.70) notes that action research ‘goes beyond the usual concerns for consent, confidentiality and respect for participants’, as genuine participation is seen as collaboration. In this area of research, negotiation is a key issue.

In our view, consent for individual interviews, and consent for working with groups involved two separate instances of consent seeking. Groups were asked for their permission and in addition to that, people involved in the groups were welcome to take part or not in the research, as they wished. All groups reported they had discussed our letter with members at a meeting before the decision to invite us was taken, as in all groups the decision making process was, ostensibly, led by people with learning difficulties. On arrival at the groups we double-checked this with group members, as we could never be certain how the supporters had explained the work.

Jenny Morris (1998), in her research on the experiences of disabled children and young people, describes how a human rights and social model perspective can inform the whole process of information gathering. For example she points out that:

Informed consent is not something that needs to be established just at the beginning of contact with the participant but should be an inherent part of the relationship. Disabled people may experience the following barriers to giving informed consent at the beginning of the project...They may not receive the information because someone else decides it is not appropriate. The information may not be in an accessible form. The channel of communication back to ...the project may not be open to them (p.6)

Consent for interviews and groupwork, then, was asked of the person as an individual alongside an explanation of what questions would be asked and how confidentiality would work. Consent was later sought for using information from fieldwork observations and groupwork.

However the experience of working in People First had taught me that there were many signs to indicate discomfort or hesitancy that did not rely on spoken language. Consequently it was important to be mindful of a person's holistic communication (Caldwell, 1996). It is impossible to say if this worked all the time but it was my responsibility as a researcher to double-check.

The Research-team set out to treat all participants as equals with respect and courtesy, making it an easy option for people to decline. As a team we shared the belief that adults can make their own decisions and therefore did not seek the views of others to confirm the decisions made by group members as, in the team's view, that would be patronising. People who made any indication that they did not

want to be interviewed or involved did not have an interview or involvement. Completely out of our control was whether particular members were invited in or not on the specific days we were there.

Inclusion - Validity and Reliability around Communication

We needed to think particularly about communication barriers, which might raise questions over validity, reliability and comprehension during interviews. Some studies looked at the types of questions being asked and the process of asking that would offer most reliability and validity (Bull, 1995; Memon, 1993; Milne 1999). For example it was found that people with learning difficulties tended to be more acquiescent than the general population and that asking yes/no questions led to more being answered 'yes'. An example to counteract this is to break the question down into as much separated detail as possible, and then ask both possibilities. We talked about this in the team when preparing the strategy for interviews. However detailed questions can only be asked of people who have some level of receptive and expressive language, and this was not the case for everyone the Research-team planned to work with. This highlights deficits in relying on interviews rather than observations.

Campbell (1995) stated that there is no such thing as a language that is impossible to penetrate and suggested getting to know the people well, spending time in observation and coming to understand the triggers that open up familiarity. Likewise, Caldwell (1996) remarked that the researcher could take on various roles, such as 'football supporter', 'Shaking Stevens' fan, or 'fashion commentator', in order to build a bridge into effective communication. The point

was to reflect on where an individual was coming from, and the issues that were important to that person, when trying to form some kind of rapport.

Caldwell (1996) also maintained that it was important to use a person's own language, which is verbal or otherwise. Observing the person and starting to recognise their established pattern of communication could develop this. Caldwell found that one could gain a person's attention by starting to echo and copy the form of communication used which could then be built on using variation to become more expressive and diverse. Although these ideas of mirroring were useful to be aware of and try to use, they are probably more fitting for informing long term and sustained support or 'immersion' in a long-term study.

Interestingly, Davies, Watson and Cunningham-Burley, (2000), in setting up their study on the importance of power within the research relationship, were interested to develop new research tools to aid the process of communication with participants. However in the end they did not employ the use of any pre-prepared or structured activities as they recognised that each individual had different competencies and experiences. This implied there was an important notion of a creative and open outlook in getting to know each individual.

From the experience related through other studies and my own experience, I maintained an open mind as to the communication that would be fostered with each individual. Most people involved in the groups were verbally communicative, although the level of my understanding was sometimes to be challenged due to lack of familiarity. But certainly people involved in the study

with the label of learning difficulty did not fit pre-determined boxes of ‘type’ of communication.

Accessibility

A prime overarching concern of the research was to ensure accessibility, as far as possible, at all levels (see Atkinson and Williams, 1990; Chapman and McNulty, 2004; Townsley, 1998; Traustadottir and Johnson, 2000; Walmsley and Johnson, 2003). This was discussed in minute detail during the research planning and was to be returned to at each stage of the research cycle including writing up. The team requested that the findings of the research should also be written as an accessible report at the end of the project and this would be distributed to the groups we had researched. These reports were also to be taped and a feedback session held where participants would be invited to share the findings in person. Louise and myself are committed to this process after the project has been completed.

Piloting the project – the importance of reflexivity

The first visit to group A (January, 2002) acted as a pilot run for the rest of the project. I stayed with a friend who lived nearby for the week’s visit. I went alone for two main reasons:

The Research-team initially planned to visit groups twice, once where I attended alone and the second time with the whole team. This proved to be financially impractical.

At this stage of the process it seemed important that the study should be researcher-led which is why the idea of an initial visit alone had seemed necessary. Eventually I visited group A and group B (March 2002) alone for a week each, but the team paid a follow up visit to group B (May 2002) where we worked as a Research-team. This provided comparative material between solo research and teamwork and was useful for the purposes of triangulation. It also showed the tension and later development between the interests of the Research Team and myself.

In pilot group A, interviews were conducted with advocacy support-workers, individual members and groups of members. I took a range of photographs, read the organisation's documentation, observed group and management meetings and ran a group session with members on the role of support. I also observed in and around the office environment, specifically noting communication. Two members who had been in the group a long time, and said they were dissatisfied with the group, approached me and asked to be interviewed outside of the office.

During the week, although the process was enjoyable, I came to feel increasingly uncomfortable, because I was not conducting the research in an inclusive and participative manner. It felt to me there was much I was missing, because I did not perceive the group through the experiential perspective of a person with learning difficulties. I also thought how much easier it could be for a member to talk about their feelings with a member from another group rather than with a person perceived as a support 'type' of person. It seemed possible that a support 'type' of person may be perceived to have intrinsic power because of the observed

ability to read, write, facilitate, make notes, and all the other factors that would have been experienced by people reliant on others in the past. This was documented clearly by Atkinson (1989, p.69), where the person being interviewed commented, 'She must be very important, asking us all those questions'.

When I returned from the visit to group A, I explained my reflections and feelings to the team and then to my supervisors. The team was keen to get involved immediately in a more tangible way and understood my reservations. On request I wrote a paper to explain and justify the reasons for my change of plan and how I wanted to focus more on the actual process of inclusive research as a total process rather than a segmented process that was added on. I also felt I needed to analyse that process as part of the project. A change in plan was agreed by all and the subsequent four groups (B, C, D, and E) were researched as a team. This was the point where it became clear we did not need a sixth group to research as the research aim had widened and become far more complex. The dates of the research visits can be found in Appendix 11.

Despite the lack of inclusion, I do not view the information gathered from the pilot group A as flawed and because of this I have used it. Later in the course of the study it was used as comparative material in two ways. It was used in the analysis of data by the other members of the team, and to compare my approach as a lone researcher with being a team researcher.

Incorporating feedback from the pilot

The change of plan to research the groups as an inclusive team only, was a large shift in the emphasis of the project. Through the work I had done in group A, I had come to realise the benefit of recording ‘*communiograms*’ (see Appendix 4; a network of interactions) between advocacy support-workers and members at key meetings, so I applied this method at all of the other groups. This I did individually, as the writing and recording could be complicated - so it was not used a team method. It was also apparent that the workers had issues that they wanted to focus on and this would be an important aspect to feed back to the groups at the end of the research.

Additionally I was made aware from situations that had arisen at group A that observing presentations was a rich source of information for understanding the interactions and power issues between supporters and members. This was added to the subsequent collection of information. In contrast, some things required less attention. There were key questions only that needed to be asked about the conception and construction of policy documents and business plans, the main point being, were they owned and accessible to members or just advocacy support-workers? All of these points were noted for future visits.

Reflecting on Research Relationships in the pilot study – power in the field

There are issues around the intrinsic power of a researcher (Atkinson 1989, Goodley, 2000), and also around the relationships between people with learning difficulties and researchers (Williams, 2000b).

I reflected during the week in group A, that I held some kind of power as far as the advocacy support-workers were concerned. Because I was researching this subject having been a supporter (and this was made known) some workers appeared to view me as a kind of expert on it. This manifested itself when they apologised to me if things they had planned did not run smoothly. It appeared that they were feeling judged in their role, despite the explanations to the contrary. This may have been where having a background as a supporter was not helpful.

There were other supporters who seemed to want to challenge me, investigate my credentials for such a task and question my ability to have an open perspective. All of this was fascinating material to see how it affected members and other supporters. In essence it was background information and my intrusion into their lives set off an alternative dynamic of explanation and justification within their own reflections that could be observed and questioned.

Due to my own experience in People First support, it was quite easy to participate in group sessions and therefore take part in participant observation. When it was suggested by a supporter at group A that I facilitate the group to discuss the question of support at a meeting, I felt equipped to do so (and interested in how I was approached). It was important to be flexible and fit in with what was happening, as there were a lot of diverse activities in the group and it would be impossible to spend time in a group as a non-participant.

I felt at this point my experience in People First was a useful tool, because I had experience of group dynamics and how to make questions and discussions

accessible. However, because of my background I also had to be extra mindful to stand back and remember it was primarily **research** I was there for, not support or information giving, though it was inevitable that this happened to some extent. This dilemma of role-blurring and role contamination (Robson, 2002, p.187) is apparent in a number of other researchers' accounts where researchers found themselves also acting as advocates (see for example Johnson, 1998 p.219). Partially it is due to the expectations that some members in the group have of those without the label of learning difficulty - a powerful person to whom you can ask for help in problem solving.

I was emphatic in explaining to people that I was not an advocacy support-worker to their group, nor was I there to have any power of decision making, but just to look at how they worked. This in itself implied an elevated construct, that I was in a position to see how others worked together. People perhaps felt they were being judged. I tried to make all this clear... *'I'm interested in how People First groups work together'*; *'I hope it will be helpful to your group'*. One person thought I was a teacher and another that I was from a service agency. Furthermore it was difficult to explain 'research' to people who had never come across the concept before. It was important to try and appear 'role neutral' in order to build rapport and to avoid acceptance of the group advocacy support-workers' embedded perceptions of each individual (see Davies, Watson and Cunningham-Burley, (2000)

Following the influence of feminist research I also aimed to 'give of myself' (see Oakley 1981). I took with me photographs of my children and family as well as

members of the Research-team. I was open to personal questions as well as questions about my values and work. I sat and listened to what people wanted to talk about by having coffee or lunch with them, as I knew from past experience that these times were common points for supporters to separate from members. In effect I tried all the tactics I knew to reduce my intrusion and sense of power and encourage an atmosphere of friendly interest. Only the participants can really judge if that worked although it is not so much a technique as a commitment to openness and acceptance of people.

Reflecting on research relationships – power and the Research-team

Managing issues of power within the Research-team was challenging. This was because I was part of the group as well as supporting it and there were several layers of reflection to work through. The benefit in working with the Research-team was the length of time prior to the research during which we had established trust and rapport (see Roets et al 2004). Additionally, I was equipped with information and knowledge about research that I could take to the group. Despite Malc's views recorded above, I did not feel an equal partner in this project, because I knew a lot of the discussion that arose within the group started from the information I brought to it. This is not to deny the team members' expert role in the light of their own experience. As Carl Rogers (1961, p.23) states: 'Experience for me is the highest authority. A touchstone of validity is my own experience'. As time went on and we looked at other research projects this balance of power shifted and changed, but through the stages of this research project, I was acting as a 'team leader' and essentially, it felt like 'my' project.

Although I had access to academic knowledge and could contribute this to the team, I was not in a position to pay them for their own contribution. This is a major deficit according to Aspis (2002), who regards non-disabled researchers as building their careers on the backs of people with learning difficulties. It did seem that I was in a privileged position. As Walmsley and Johnson (2003, p.180.) state:

Ultimately it has to be acknowledged that the allies,
the non-disabled people who support the research,
stand to gain most in career terms.

It is easy to highlight positive outcomes for co-researchers and perhaps gloss over issues of exploitation (in the light of the demands of emancipatory research).

Indeed, Van Hove (1999) and Williams (2002a) make clear that co-researchers should be paid the same as anyone else. It is a position the Carlisle Research-team itself has demanded in other areas of its work. It was not a possibility with this project.

Yet when the Research-team worked together it was exciting. People turned up and were enthusiastic. It seemed there was more to the research relationships within the team than payment. Payment is often referred to as an answer to the materialist inequality of the relationship between the researcher and co-researchers (Zarb, 1992), but it is not as straightforward as it seems. Walmsley, in Walmsley and Johnson (2003, p.155), reflects:

In one project in which I was involved, I came
speaking the words of equal payment. This was
a user controlled project however and the users
declined the opportunity to be paid. Why? Because
very junior research assistants can expect
less, after deductions, than the benefits/pensions

that these would-be researchers obtain as people with learning disabilities. Not only that, when the project ended... (it) might make it very difficult to resume claimant status at the previous rates based on disability premiums.

Other forms of negotiation were equally important to the people I was working with. We agreed that I would give my support free to their projects, in exchange for their free support of this project. In effect, like the team, I became a volunteer. This is possibly a different experience to that of Mitchell (1997), for example, because her project was the only one running at the time. For our team, it meant the research took more time because of different events happening²². Our negotiations to support each other dramatically increased the amount of work we were involved in together. This exchange of skills and time could be viewed as an extension of the idea of reciprocity and be traced back to the influence of feminist researchers (Oakley, 1981; Mies, 1983).

Inclusive Research Methods in practice

This section describes the different types of methods the team used, and what type of support that entailed. It also highlights the different roles I occupied at particular stages. Methodological issues in process are also further highlighted in Chapter 9 under the section ‘framing the project’, and could be read in tandem.

The table of the data collection strategies (below) shows who was involved in each activity within each group. Although there is much consistency across the groups, some different strategies were used experimentally and to check data collection.

²² For example the ‘History of People First Workshop’ (owned by the team and not used within this project) took a number of months to organise, practise and hold, right in the middle of this research fieldwork process, July 18th and 19th, 2002.

In the case of support workers, interviews were shared to uncover differences in what was found. In the case of body maps, these were used to try and develop new techniques, as was the case with communiograms (see Appendix 4). More detailed accounts and explanations are given later under each section in Chapter 9.

GROUP	Support worker interviews	Member interviews	Group Work Body map	Group Work Discussion/ Planning day	Communiogramme	Observation	Field notes	Analysis
A	R	R		R	R	R	R	R
B	R, L.	R, L, A, M	R%	R,L,A,M	R	R,L,A,M	R,L,A,M	R,L,A,M, E,N,S
C	R,L	R,L		Rx2, L	R	R,L	R,L	R,L,A,M, N
D	R, L,	L, A		R, L, A	R	R,L,A	R,L,A	R,L,A,E, M,J
E	R	A,L		R,L,A	#	R,L,A M*	R,L,A,	R,L,A,M, E,S

Table 1: Breakdown of data collection

Key: Initials relate to first name of team member

Notes : *M - Where M travelled to fieldwork site but was later ill
- Not undertaken as support worker did not remain in room when members meeting.
% - Tried as experiment to see if effective, (space and resources available)

Acting as an Observer

The observations of groups and individuals needed separate permission, as discussed earlier, following Morris (1998), as each event was construed as a separate occasion. In group A, it was uncertain whether I would be allowed to stay and observe the management meeting although eventually the advocacy support-workers conceded this (the members were open to it in any case). However, there was a need in the field to be clear about roles. I was asked to provide support to an

individual, who needed to leave the room frequently, which would have meant missing parts of the meeting. I said I was unable to provide this intensive support, as I needed to observe the meeting, which involved staying in the room. I could have done the support and presented myself as a participant-observer, but my curiosity to observe the (one-off) management meeting made me resist that role. However it was agreed that I could stay and just observe. In a sense this reinforced my role with the advocacy support-workers as a researcher, over and above my experience as a supporter. If I had not been able to stay for the duration, I would not have discovered the effectiveness of the communiogram²³.

There were also issues around looking at documentation. The pilot group supporters were guarded about documentation being seen, especially policy statements. However, when the supporters were in their office, a member simply passed me over a box of policy statements one day to see if I was interested. I was uncertain how to react, so I made sure it was obvious I was looking through it when staff returned to the room, to ensure the episode was not hidden.

This was clearly an ethical dilemma and one to which I may have reacted wrongly, but it had the effect of making me more vigilant in subsequent visits. The wider context of the question was – from whom does one have to seek permission in a People First group? My initial thoughts had been, ‘the members’, but on reflection it was probably the ‘management committee’, who in this instance were not just members. Swain et al (1998, p.25) note that ‘the practice of fieldwork (can be) open to manipulation and the pursuit of the researchers’ vested interests’. I could

²³ I have given the name ‘communiogram’ to the drawing of lines and frequency of verbal

have easily manipulated the situation in a covert manner by asking members to give me things to look at. Acting as an observer then brought its own issues around power, and dilemmas over whom to relate to and in what context.

Supporting the Research-team to do observations

The team undertook observations, sometimes as participant observers and sometimes as observers. In the planning stage the team developed a taxonomy (a list of points to be aware of) for observing the power relationships in groups within an office base in terms of communication, participation and passing of information. The components of this taxonomy were grounded in the issues emerging from discussions of the team at their planning meetings when talking about power within a People First office. This had stemmed from Andy's comment that *'if support workers go upstairs to talk it makes you feel uneasy'*. (RG notes: 19/07/01).

This taxonomy was used at each location, apart from Group E as they did not have an office:

interaction between support-workers and members at meetings.

LIST OF POINTS TO BE AWARE OF

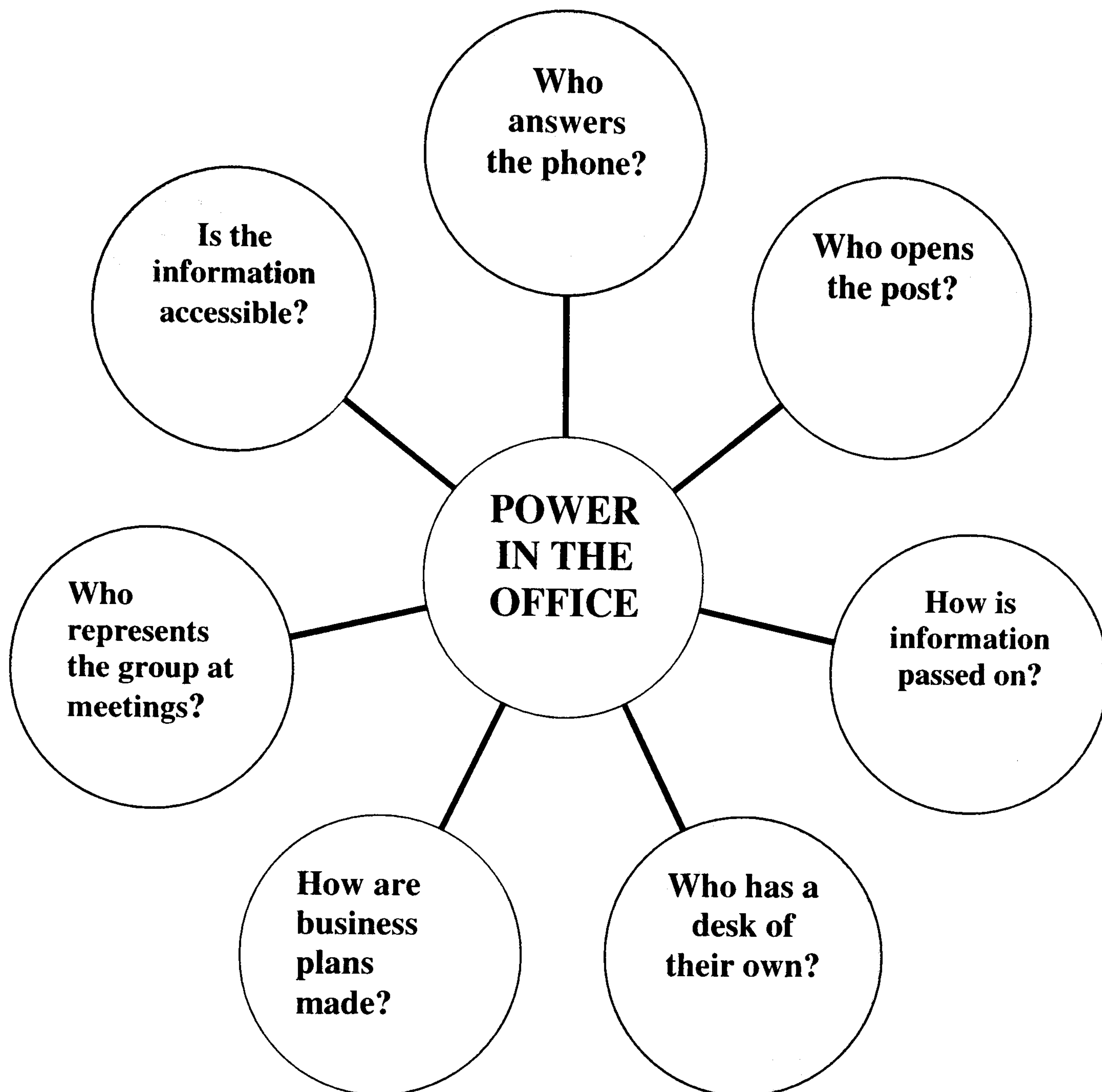


Fig 1: Taxonomy for observing power relationships

The observations were planned and we discussed at the pre-fieldwork meetings how to share the task of observation so that opportunities could be sought. Other observation was around just ‘being there’ and seeing what emerged (Silverman, 2000, p.202). Members of the team recorded their observations, either by taping them for transcribing later, or by writing or typing them out themselves.

By agreement, these notes were recorded before any group discussion or reflection could take place, so that others’ perceptions were not able to influence each

individual's thoughts. This was sometimes difficult to achieve especially when the team consisted of five people, and a lengthy journey was involved back from the site. However it proved a useful way of managing information. Interestingly there was definite repetition and contamination of findings on the one occasion the agreed plan failed to happen, where two members had discussed the events of the day on the way back to the hotel. The notes were usually quite short but were always a word-for-word description from each member, so no interpretation had taken place.

In the evenings the group would discuss the events of the day, after all the recording had taken place. This was inevitably the informal start-point of data analysis as discussed later.

The role of supporting the Research-team in observations was simply to enable their activity to take place and subsequently for their observations to be recorded in a way that suited each individual the best.

Conducting interviews

The main strand of the research that was my area of responsibility was the interviews with support-workers. These were informal, semi-structured interviews, allowing space for people's ideas to emerge (Smith, 1995), following action research principles of emergent information. With advocacy support-workers there were seven broad questions to be answered (see Appendix 5), but it was flexible as to how we got there. The interviews were lengthy, generally around an hour and sometimes more. This was planned in order to provide full and

rich material for analysis, especially from the ‘senior’ workers who were known to have been working for longer periods of time within the groups. The interviews with senior workers were planned to be analysed by a process akin to Interpretative Phenomenological Analysis (IPA); (Smith, 1995; Smith, 1996).

The aim of IPA is to try and understand **detail** in the person’s view of the subject being scrutinised at a level of individual perception and personal experience rather than seeking an ‘objective’ viewpoint. Therefore much attention is paid to the words of the participant. Simultaneously, IPA recognises the dynamic process of research and understands that access to interpretation is also reliant on the researchers own viewpoint. Hence the term Interpretative Phenomenological Analysis is used to describe exactly the two components of the approach (Smith, et al 1999, Chapter 14).

In IPA, interviews are taped and transcribed verbatim and then put through a process of detailed qualitative analysis, finding key themes emerging in the interviewees’ talk whilst accepting that the emergence of these themes is also dependent on the researcher’s own perception. In other words it is an interpretative activity.

The questions asked were based on the questionnaire used to research the role and experiences of advocacy support-workers in the Northwest of England, (Chapman

1997²⁴; see Appendix 6). This had indicated the questions to ask when trying to uncover what workers understood of People First and its tacit ‘philosophy’.

Interviews with members also relied on a few key questions though these tended to be much shorter interviews (see Appendix 7). During interviews there was a checklist of questions to cover.

Supporting the Research-team to do interviews

Niall McNulty, who was employed as a support worker at Carlisle People First, acted as a general supporter to the Research-team, rather than a researcher working in collaboration. When Niall and I supported members of the Research-team to conduct their interviews with other members, I would either have prepared their questions in large print with illustrations, or Niall or I would unobtrusively provide verbal prompts depending on the researcher’s own preference. Interviews were taped (unless the person requested otherwise) for later transcription and analysis. Louise Townson helped with the transcriptions. A few interviews were recorded in writing and then later typed. Most interviews with members across the groups were conducted in a private room with the exception of one group, which did not have an office base. Here we conducted interviews in a corner of a room at the local community centre, and later in a quiet space in the local pub.

When supporting other members of the team to conduct interviews, there were times when the interviewees would look at me or Niall to respond to a question, or

²⁴ The questionnaire was designed to record the views of advocacy support-workers in the NW of England about their role. This followed a workshop in Cumbria in 1997 on ‘Power and Control’, which was open to advocacy support-workers in the NW of England. This workshop was designed and facilitated by myself, Mike Parkes and Ian Wilson.

ask questions directly to me or him rather than the interviewer. This indicates that people have an expectation that the person without the label of learning difficulty is the person holding power and the person to ask.

On these occasions we would use the techniques learned in our previous support roles of directing eye contact at the interviewer, not the interviewee, and of keeping silent so the interviewer would use that space to reply to questions. If my name was used in a question from the interviewee I would repeat the question prefaced by the interviewer’s name to pass the dialogue back. I would also place myself with my back slightly turned towards the interviewee and my face towards the interviewer to make direct eye contact with the interviewee more difficult. I would otherwise tend to look at the tape or write notes and keep my eyes and head down. When we entered the room the researcher would negotiate seating and the start of the interview, and would summarise at the end. These techniques tended to work fairly swiftly and redressed the balance of power. Where it was possible I would take a photograph of the interview in process after gaining permission. The point of research support here was to stay in the background and leave the task to the main researcher at that point in time. In total 42 interviews took place. The details of who interviewed at each group are to be found in Table 5:

No	Detail of Interview type
15	Interviews with advocacy support-workers conducted by myself
8	Interviews with members conducted by myself
16	Interviews with members conducted by Research-team members
3	Interviews with advocacy support-workers conducted by Research-team members

Table 2: Number of Interviews

Facilitating group work

In all of the groups some groupwork was observed or took place, facilitated by myself or together with the Research-team (see Walmsley, 1990). Group interviews were seen as useful for this research because of familiarity, drawing on people's experiences, that is, of both the researchers and the researched (Robson, 2002, p.283). One group held its own Business Planning Day, and that was used as an example of groupwork, because the advocacy support-workers facilitated members to develop their own business plan.

In four of the five groups, actual sessions on members' views of support work were facilitated without their workers being present. These were conducted within the space and confines available. In line with our plan of trying out different methods, in one group it involved making body sized and shaped paper outlines of support people with members filling in the required qualities on one body shape, and the less desirable points of advocacy support-workers on another. Although the description of this appears quite polarised and limited, the discussion these groups generated was rich and detailed, while members related their personal experiences. This proved to be an effective method because it was visual, audible and peer-supported. These again were techniques that were familiar in the working of People First groups. It also relied on members as 'experts' of their own experience (Rogers, 1961) and seemed less threatening than an interview environment, where people sometimes worried if their answers were 'right' or 'wrong'. The position of researchers as powerful people, coming in from the outside, was going to be impossible to avoid, but we planned that our efforts towards a more equal relationship might at least help.

This description emphasises the points about the merging in and out of different roles within the research process, particularly for myself. However it became clear that other members of the team were developing support aspects to their role as time went on. This is discussed in Chapter 9.

A case study of how the team prepared for work in the field

When we worked as a Research-team we had to be well organised. Five of us went to Group B, 400 miles from Carlisle, which turned out to be the largest team experience. We travelled in a minibus from Carlisle and stayed at an accessible hotel a few miles from the group's base. The five people included Niall McNulty (who was acting as a supporter to the team), Louise Townson, Andy Docherty, Malcolm Eardley and myself. I had to shift between the multiple roles of researcher, manager and support to the Research-team as well as being a member of the Research-team.

The team were knowledgeable about the research, as they had been involved in planning it from the beginning, as well as hearing about and discussing previous studies, the legal and historical context of the groups, and support work (see Chapter 2). There was a fluid agreement that I would concentrate on interviewing advocacy support-workers and the rest of the team would interview members. We would all take part in observations and groupwork.

The night before our first visit to the group, we held a team **pre-fieldwork** meeting to go over the information we already had and to remind ourselves of our roles, and how we would divide up tasks.

The pre-fieldwork meeting (see Appendix 8) lasted an hour and a half. We checked through the equipment so everyone knew how to use the tape recorders and camera. Some interesting questions emerged. Andy asked if we were really there to judge the group against the team's own People First group. This led to a discussion about objectivity, and also orientation. We went back over basic rules for ourselves such as the importance of confidentiality, listening without intervening, and of giving open choices and open-ended questions. We established an action plan for writing up fieldnotes and agreed that no discussion would take place until we had finished recording all the fieldnotes for the day. The team discussed gaining consent for interviews and the process of fully explaining what we were doing. We agreed a statement that we were there to look at the group, as we were interested in how People First groups worked. The Research-team was also interested in the history of the group, for their own project, and had further questions to ask in that area. I asked the team to prepare themselves for evading the question that would almost inevitably be asked, "How do you think we are doing so far as a People First group?" The pre-fieldwork meetings were crucial because with the travel and other issues going on in people's lives, it was important to have a time of focus and reorienting close to the event.

Supporting the team in Data Analysis

According to Walmsley and Johnson (2003, p.169) and as discussed in the previous chapter, much literature about inclusive research falls short of the analysis stage:

Many inclusive researchers, including ourselves, have held back in relation to data analysis because of the perceived need to work in ways that enable people with learning disabilities to come alongside. ...why is methodological sophistication permissible but data analysis is not?

Carlisle People First Research-team (2004, p.73) has described their approach to data analysis and how important they feel it is for all stages of research to be inclusive and person-led:

We are not following someone else or being partly included, which also means partly rejected.

The discussions within the Research-team led me at an early stage to expect inclusion in all areas of the project with data analysis being no exception.

In this project, to enhance validity, there were four levels of data analysis, the first being **the team researchers identifying their own themes**. This was facilitated by going back over the minutes of the research meetings and discovering what had emerged in the discussion around the importance people placed on aspects of the research. The first listing of this was collated six months into the project. It showed that the points in order of most concern to the group were:

- accessibility
- the process of how the research group worked together
- the problems of people not being believed
- the issue of support-workers

(Carlisle Research Planning Group: Emerging Issues and References, 19/03/01).

This implied that the process of research was more important to the group than the subject of research, validating the comments by Aspis (2002) and People First National (2001).

Ten months into the project, the team started to discuss issues around advocacy support-workers and what they thought might happen in other groups. Most of the themes that emerged were negative (in the light of what they would want from support themselves) and were based on experiences they had with various workers over the years:

*There need to be stricter rules; they need training;
they shouldn't whine; they should ring if they are going
to be late...*

(RG meeting notes: 19th July, 2001).

These ideas were used as a basis for the first level of data analysis, around how often the identified themes were observed and referred to during the course of fieldwork.

The second level of data analysis was the **themes that emerged from the fieldwork**. These were listed as themes that the Research-team had not previously thought about, but had discovered during the process of research. This process of analysis started informally, early on in the fieldwork (see Coffey and Atkinson, 1996) on our evenings spent reflecting on the day's work. Later we organised times and dates to meet to specifically look at analysis. This activity went on for over a year in total, partly because of staggered fieldwork periods, and

partly because it was a time consuming process. However, there was a concentrated time of around six months where most of the analysis happened. These themes from the fieldwork were not in any way testable against prior knowledge, as the first set of themes, but were a new level of knowledge gained from the data. These were developed from:

- the team listening to the tapes of the interviews with advocacy support-workers
- listening to the tapes of interviews with members
- from observations and groupwork within the groups.

As the team worked through the data, ideas of recurrent themes were suggested, discussed and agreed by the group. These are shown in Appendix 10.

The third level of data analysis was an extension of the second, the thorough analysis, akin to the process of IPA, of **emergent themes within the senior support-worker interviews**. These were carried out alongside and beyond the second stage analysis as transcribing was a lengthy process. The themes in IPA do not necessarily set out to achieve ‘data saturation’ as in grounded theory (where no new themes are emerging from the data), which assumes there is a theoretical endpoint to the analysis. Instead they aimed to reach a degree of ‘internal coherency’ or ‘persuasiveness’ (Smith 1996). The sample was based on two practical principles:

- to gain as rich an understanding of the role of advocacy support as possible, within the limitations of the study and in connection with the other areas of fieldwork and analysis
- to achieve a degree of internal coherency within that part of the project .

Generally IPA studies rely alone upon the small sample of data collection that is used, as it is regarded as ‘highly qualitative’. However in this study, because of the involvement of a team in inclusive research, I wanted to set out different types of methods to improve reliability.

The fourth level of data analysis involved **the reading and discussion of documentation and photographs** taken on-site. These not only served to remind the team of what happened but sparked themes that had not previously come to mind.

The preparation of data for analysis was at all stages part of discussion within the Research-team. We worked out the best approach to meet each team member’s strengths and abilities. Because of this the practice of listening to tapes was highlighted above transcription and reliance on reading. For example, team members would be given tapes to listen to before meeting to discuss them. Likewise, discussion in the team was prioritised over individual work. Also, frequency and continuity of meetings to aid memory and understanding was of prime importance. This is discussed again in greater depth in Chapter 9.

Conclusion

This chapter has outlined the actual methods used and adapted for the project, based within a qualitative and inclusive paradigm. It was informed by Walmsley and Johnson's (2003) framework, which takes into account the specific needs of people with learning difficulties as researchers. This project set out to build upon this framework.

The approach to the research aimed to involve people in the whole process and maintain their integrity over ownership of different aspects of research. This was eventually achieved by splitting the work into different projects and agreeing to support each other in those projects. Although the team discussed at length the People First National (2001) notion that people without the label of learning difficulty should not be involved in the research at all, the group decided that they did require support for research and therefore we worked in collaboration, for all of the projects.

A number of lessons were learned during our preparations for fieldwork that changed the course of the way we approached the project. It was also clear that people's roles in the team developed and changed throughout the experience. This is discussed in chapter 9.

My role clearly changed at different stages and times throughout the process.

Although I took on a variety of roles it became apparent through emerging knowledge that the supporter/researcher role needed to be separated. The fact that I acted as a leader or manager to the team reinforced my separated researcher

role. The salient point was that a researcher has their own voice, whereas the supporter is trying to facilitate other people's voices. It is difficult to do both, and to change between both, but the limits of the study dictated that I had to change between roles within the fieldwork context. However changing between roles did allow an experiential insight into the differences between each role – and also some of the tensions inherent in the advocacy support-worker role.

Another important issue came to the fore around the debate over whether people can be involved in the whole research process because of impairment issues. This project showed that this particular team of people could, but at different levels based on personal attributes. It implied that polarising people into different positions does not help us to understand the qualities that can be brought into the research process by the skills and abilities of each individual, or indeed the opportunities on hand to learn from each other.

The strength of this research approach was that it provided a unique double perspective. That is, there were researchers acting as 'insiders' working with support-workers and members. This double perspective proved to be a good methodological strategy and is discussed further in Chapter 9. Reflexivity was a primary activity within the team, without which the danger of 'blurring of roles' would have undermined the quality of the research process and findings.

Overall, the methods used in this research project were adapted towards use for team ownership and participation. For the team, they were the most likely methods to be able to facilitate answering the main research questions. During the process

we endeavoured not to build dependency on research supporters, but to explore ways of enabling team members to be as independent as possible, and in control of their own area of research. Given that the team has since developed their other projects and have identified the need for 'person-led research' (Carlisle People First Research-team, 2004), I feel this process has been largely about developing and challenging previously held views and assumptions. By that I mean, people with learning difficulties have been regarded (as a group) as unable to participate in certain aspects of the research process. This assumption has been challenged in this project. The process has sought to develop people's skills as researchers. However it should be remembered that the Team was made up of people who had all shown an interest in research and had spent time in learning research skills.

CHAPTER 6

THE ROLE OF THE SUPPORT-WORKERS IN SELF-ADVOCACY GROUPS

Perspectives of support-workers

This chapter is about the perspectives advocacy support-workers have of their role in five self-advocacy groups in the UK, between January 2002 and February 2003. The interviews are the main strand of my personal research within the project. The chapter begins with some background information, using the work of Dan Goodley (2000), which this research has built upon, as referred to in Chapter 3. The support-workers are then introduced.

The major themes emerging from the question: **What are advocacy support-workers' perspectives of their role?** are detailed in the following sections through an exploration of the work role. Each theme identified had sub-themes which are also discussed. These themes emerged from the work of the team in their category analysis of the data gained, adding to it the detail from the themes arising from Interpretive Phenomenological Analysis. An example of how these themes emerged and what was involved in the analysis stage is given in Appendix 10b and 10c.

It should be remembered that the research looked nationally at five groups in depth; the findings present a snapshot of self-advocacy in action within the UK at that moment of time. A broader study of more groups could build on the results of this study. The nine main themes that emerged are listed below. The sub-themes

were decided upon through the process of analysis undertaken and agreed within the team (see Appendix 10).

1. Advocacy support-worker journey into the job
2. Models and theories
3. What advocacy support-workers should do
4. Advocacy support-workers in action and emerging barriers
5. How the process of empowerment worked
6. Issues around funding
7. Training and supervision
8. National issues
9. Service and grassroots advocacy.

After the themes are set out there is a summary of barriers and problems encountered in support work.

Background context

This section reviews the findings from Dan Goodley's (2000) study and then goes on to describe in more detail the identity of the support-workers involved in the study.

Goodley (2000) pointed to a continuum where support work could be rated on a scale of individual model to social model intervention. This approach was an advance on a previous bland assessment of whether support work was 'good' or 'bad', defined by Worrell (1988), Dowson and Whittaker (1993). Goodley also

questioned the assumption that service workers who were supporting self-advocacy groups were necessarily more disempowering than advocacy support-workers in independent organisations.

This research concentrated on advocacy support-workers in independent People First organisations where one would assume conflict of interest was kept to a minimum. However, adding to Goodley's continuum, this research found the working situation amongst advocacy support-workers more complex still, as even where interventions were based upon a social model perspective, the interpretations of what that meant in terms of the People First group were often confused and unstated. In this way the research develops Goodley's work.

This study also explored the perspective of members alongside those of advocacy workers around the same questions. Not only did the support work interventions depend on individual value systems and views of discrimination, but they were also determined by relationships with members and other advocacy support-workers, as well as how organised (or not) each group was.

In addition support was also affected by the stage of development within the group and significantly by the quality of communication. In sum, Goodley's (2000; 2003), work moved understanding of advocacy support-workers' roles on from a straightforward dichotomy of style, to showing a variety of approaches to support. At a further level of complexity, this research also explores the relationships between workers and members in order to consider other pervading influences on the support role.

The Advocacy Support Workers

In all, 18 support-workers were interviewed in depth. They were given pseudonyms to protect their identity, and were assured confidentiality in the treatment of their involvement.

The five groups each had a primary advocacy support-worker, or development worker (described here, by me, as a senior) whose interview was analysed through a process akin to IPA. Of the 18 advocacy support-workers, only one was a volunteer (Group E), the rest being paid workers. 12 were women and six were men:

Supporter pseudonym	Group	Role	Future plan
Yvonne	A	senior	Continue
David	A	support	Unsure
Moir	A	support	Continue
Donna	B	senior	Continue
Jayne	B	tutor	Continue
Susan	B	support	Continue
Gerald	B	support	Leave
Ruth	B	admin	Unsure
Gordon	C	senior	Continue
George	C	senior	Continue
Fiona	C	support	Continue
June	C	support	Continue
Ian	D	senior	Continue
Jackie	D	admin	Continue
Cathy	D	support	Leave
Colette	D	support	Leave
Anne	D	support	Continue
Isaac	E	senior/vol	Unsure

Table 3: the details of advocacy support-workers

None of the workers interviewed came from a minority ethnic background. This was a reflection of the make-up of the groups, which were overwhelmingly white. Support-workers were not asked their age, but the senior workers could all be

described as people in their middle age (40-55), barring Donna (Group B) who was in her mid-thirties. The age range of support-workers was from around 20 to mid-50s. Support-workers were asked their future intentions and whether they planned to stay in their present role. Twelve workers indicated their intention to stay for the foreseeable future. The next section looks at the findings on the role of advocacy support-workers, who I shall now refer to simply as ‘workers’.

Support-worker perspectives of their role

1. Advocacy support-worker journey into the job

This theme traced how workers arrived at the organisation and how they initially saw their role. The initial quotes used to illustrate points were suggested by myself and other team members during the analysis stage (and is demonstrated in Appendix 10c). These are added to by quotes I felt were similarly relevant. This process was used throughout this chapter and chapter 7. The section is divided into three sub-sections:

- Personal drive, motivation, and background
- View of the contribution of self
- Job satisfaction.

Personal drive, motivation and background

The workers I interviewed came from diverse job backgrounds and did not appear to have mapped out career plans:

My background was my mother had a number of jobs and my

*father didn't because he was dying, I had no specific career path,
I still don't by the way. Isaac, Group E.*

The senior advocacy support-workers (advocacy development workers, managers and co-ordinators) were all in their middle age and had spent a significant number of years working elsewhere. Some of these years were spent in related jobs such as participation worker, social worker, counsellor or empowerment worker.

Advocacy workers had a tendency to be 'driven' from feelings within:

- *I had a strong feeling about justice and injustice from an early age,*
Isaac, Group E.
- *I always had a bee in my bonnet about the lack of inclusion,*
Gordon, Group D.
- *It's not something you can learn, you have to have it in you first,*
Donna, Group B.

These comments implied workers found it important to convey a pervading inner sense of social justice. Not one advocacy worker I interviewed came into the job simply because it was a job on offer or because they needed the pay, or because the Job Centre had encouraged them to apply. Everyone expressed personal reasons as to why they had come into the work, including their own value system.

Although in all but one of the groups, specific qualifications were not required, three of the senior workers had university degrees and a number of other advocacy workers had teaching, counselling or social work qualifications.

A number of workers viewed themselves as allies to people in a political movement:

- *I was brought in as I'm disabled and steeped in the social model, Yvonne, Group A*
- *I like working here as there is a political agenda to work through, that's why I feel comfortable, Moira, Group A*
- *I felt this was my vocation, Donna, Group B.*
- *I came into the job because I was interested in, fascinated by the idea of what it was trying to do, Gordon, Group D.*

Interestingly, as well, a number of people viewed self-advocacy as being about themselves as well as the members:

My personality has changed, definitely, instead of sitting on the fence I fight for what I believe in and I will say, I will speak up, so I'm a bit like my members really, I have grown with them, Jayne, Group B.

Similarly, Isaac (Group E) said:

It's also about me understanding things, knowing that I too can speak out and have a right to do that...the stuff we know about People First...is applicable to everyone, not just people with learning difficulties.

Words that were used to describe feelings about moving into the role included: *excited, fascinated, enlightened, enthusiastic, potential, commitment.* All of these words were positive and suggested that workers came into their new role filled with optimism about the job.

View of the contribution of self

Advocacy workers were conscious of the qualities in themselves that they brought to the job. One worker reflected:

My qualities are more of a person to person approach.

I think I use my counselling skills in a way to actually work on a person-centred approach, if you see what I mean. I'm not totally organised and I'm not the best person to go out and liaise with other agencies. Jayne, Group B.

She saw the members of the support team as having complementary roles:

I would say the three of us together, this is going to sound extremely condescending...we are a perfect team the three of us together because the three of us work differently. It works really, really well.

Similarly a development worker explained:

I was a good listener and I was able to listen and empathise and appreciate what people want. I can assess a situation. I came in a bit fresh and brought something new in with me. I want to push things to the limit. Gordon, Group D.

On the other hand a worker with a particularly focused agenda around changing society said:

I come from a political radical family so I'm jenned up on inequality and can smell a rat and sniff out patronising attitudes. I will not collude with the inequality agenda of anyone. Moira, Group A.

Generally workers were aware of their attributes and responded easily to questions about what they brought into the groups in terms of skills. Reflexivity, mentioned earlier, was said to be common practice and most people mentioned their willingness to learn more and become better practitioners:

I do a lot of reflection. I really believe that we learn off each other and role modelling is the most powerful form of learning. I'm really aware of any negative aspects that could influence the groups, especially if I just want to just let off steam or slam a phone down or call someone everything under the sun. But I know I can't. I have to say, right, this is what we need to do... because if they pick up negative behaviour from me then it's

not empowering them at all. Jayne, Group B.

Even the supporters who were rigid about their allegiance to the social model talked about instances where they felt they could have done things in a better way:

If I'm not well prepared, others can't go and do their bit. It's great to have the opportunity to talk about it, as I feel very isolated in my job and need the chance to reflect. Moira, Group A.

Job satisfaction

Most workers enjoyed their roles despite tensions that will become clear later.

The following comments illustrated that the job had potential for great personal satisfaction:

- *I'm very positive about the future. Moira, Group A*
- *I loved it from the beginning. Jayne, Group B*
- *I'm planning on staying; I still find it's very exciting. Ian, Group C*
- *I can't imagine doing anything else now, I like what I do, I like coming to work everyday. I really enjoy doing it. People say, well this is what you were meant to do. Donna, Group B*
- *I would never leave. I think it's down to funding but I would always be involved in one way or another. I regard people as my friends. Jackie, Group C.*

On the whole, it appeared advocacy workers were motivated through their own personal values to take on the role. They were aware of their personal skills and saw the importance of reflexivity and development. Workers interviewed gained a lot of job satisfaction from their work and two-thirds intended to stay in the role as long as it was funded.

It is interesting that people came from diverse job backgrounds because it is not possible to know whether People First work was another stepping stone in a line of different jobs or whether people had ‘found their niche’. It would need a longitudinal study to ascertain this.

2. Models and theories

This theme was about the advocacy support-workers’ acknowledgement (or otherwise), of models and theories they used to base their work upon:

- The social model of disability
- People First philosophy
- Social Role Valorisation.

The Social Model of Disability

One group’s workers talked continually of the social model of disability and how their organisation shaped that model for the benefit of members:

I honestly believe that we should work towards the social model but I think that kind of ethos has got to come from the membership who understand the ethos and at the moment I don’t believe they do. Yvonne, Group A.

Her colleague also explained:

We are seeking the active involvement of other organisations who have a deep understanding of the social model and the power issues for people with learning difficulties. We are getting hold of them by the scruff of the neck and making them come here to be involved in the management committee. Moira, Group A.

Reportedly the group had floundered, not due to lack of funding but due to a lack of direction, so a review was undertaken by the local British Council of Disabled People (BCODP). This review had made recommendations that included the taking on of new staff, who were disabled, in a management capacity. It also recommended that the group employed people with learning difficulties on full salaries for any other new posts. This very much followed the model of People First National (see Chapter 2), where all the main workers were people with learning difficulties. Of the groups we visited this was the only group that employed people with learning difficulties on full salaries. The notion of working towards the social model may well be useful, in that the advocacy workers appeared clear about what their job role was. However, other workers felt there were problems with the social model and referred instead to ‘the People First philosophy’. When I asked a development worker in a different group about the impact of the social model he replied:

We’ve had some meetings about the social model over the years but I think people have found it hard to get their heads round it to be honest. I think people here feel there are barriers which stop them doing the things they want to do. Ian, Group C.

Noticeably a lot of workers mentioned the word ‘barriers’ when they talked about the problems people faced. This concept is built into the social model. Perhaps for People First groups this is a word that also has a similar meaning to the social model of disability, but is easier to understand, as it can directly relate to people’s own personal experiences. This is by way of contrast to the overall concept, which is more abstract.

Most advocacy workers described the groups as being part of a movement, even if they felt the members didn't understand that:

Members are part of the movement but they aren't conscious of that,

David, Group A.

And:

I found out about the People First movement...it's not just about speaking out about services but speaking out as a human being... It's a movement, part of a national movement, an international movement. Isaac, Group E.

People First Philosophy

In the main, advocacy workers referred to the 'People First philosophy':

There's a philosophy and a way of working ...if you start with the ethos that every person with a learning difficulty has the right to control their own life, I think that's a great starting point but we have to learn how to network and all pull together. It's easy to get into it and do your own thing, but that can be counter-productive. It's a young movement. Yvonne, Group A.

In addition, workers described what they saw as 'People First', or what it wasn't, and summarised how they interpreted it:

- *People First is not about organising social events. Donna, Group B.*
- *People First is people standing up for themselves, getting what they want, the same rights as everyone else. Colette, Group C*
- *People First stands up for people and supports people to have opportunities in life that they otherwise won't get. I like the way People First philosophy is to try and shut the day centres and shut long stay hospitals...I'm learning all the time and constantly being reinforced with the People First way of things. Gordon, Group D.*

What exactly the People First philosophy is, was not explicitly stated but was regularly used as a reference for actions the workers undertook. For one advocacy support-worker the whole idea was questionable:

I don't think there is a philosophy, there are no commonalities. I thought there was because everyone told me there was... groups are more member-led but some groups are set up by the local authority rather than self-management and participation.

She added:

There's a very strange and confused notion about People First groups. Who are they run by? Moira, Group A.

This posed the question of whether there was a philosophy at all, or whether supporters simply thought there was one. If they thought there was one and felt they knew what it comprised, did that indicate there was one? This issue will be discussed in depth in Chapter 8.

Social Role Valorisation

Two other groups' supporters (Group B and Group E) mentioned the importance of Social Role Valorisation and how that informed the basis of their work, as they tried to ensure people they worked with moved into valued social roles:

It wasn't until Wolfensberger came in that people started to look at individual's needs rather than medical assessments. Isaac, Group E.

I would say one of the most useful courses was Social Role Valorisation, definitely. Jayne, Group B.

Her colleague mentioned:

We do take notice of SRV. We base a lot of our school's project on that. You got the history of disability included and we have people who have lived in [a large hospital] and they say how they feel valued now and how their roles have changed. So we use SRV quite a bit. Donna, Group B.

Interestingly, Group B workers made no reference at all to the social model of disability but rather to the 'People First philosophy'.

Some workers were more disillusioned especially the three who were on the verge of leaving their posts. It was as if their initial optimism had not been realised and they had become disappointed by the complexities of the work. Two in particular spoke about how the job role had changed due to changes in the group. Newer groups forming from the original group, which had resulted in fewer members, had sparked this:

I'm not much of a supporter now; I'm just someone in the office. Maybe my heart isn't in it as much as it was, it's not my eternal passion anymore, I have other things...Cathy, Group C.

Her colleague said similarly:

People don't know where we are heading. They don't seem to be aware of what People First does...I don't think the membership know where we are going. Colette, Group C.

When I asked what would have helped them to feel more positive in their support role Colette added:

It would have been good to have a basic foundation of knowledge of history of People First, not just from members but from support staff.

In terms of influences, most workers mentioned some kind of model, movement or theory that they were working towards or which informed their work. Discussion around the social model seemed to imply that it was an abstract notion, complex to implement and difficult for people to understand. In contrast, the 'People First philosophy' and the notion of 'barriers', had a similar theoretical impact but in a more accessible way. One worker addressed this by saying:

I was fascinated by the lives they had lived, the kind of parallel universe that they lived in to the universe I had lived in. It was the lack of rights people had and they were denied access to lots and lots of things that they could make use of and take advantage of with the right kind of support. ...There was so much potential unlocked in people ...there was a huge amount of protection, they could have done so much more with their lives. Ian, Group C.

Although this worker did not explicitly use the notion of the social model in his explanations, he was clearly influenced by the same ideas.

On the whole, advocacy workers reflected on their practice and were concerned as to whether or not their actions empowered or disempowered the people they worked with. For those with an explicit social model agenda, the aim of the organisation was more important than the details around the specific people they worked with. For example, in speaking about members who were part of the management committee:

I'm going to be a much harder taskmaster. People will have to work hard and people will have to take up their responsibilities. There will be relentless training and if they miss three meetings then they will be out. Yvonne, Group A.

This contrasted to the more 'person-centred' groups:

We just get on with anything the members throw at us.
Donna, Group B.

The tension between the needs of individuals as opposed to the needs of the group or organisation is discussed in depth in Chapter 8.

Advocacy support-workers worked, in the main, to some form of disability inequality agenda, whether it be the social model, the ‘People First philosophy’, or SRV, and this informed them about their role in a very generalised way. Those who spoke of People First as a movement reflected that it was a very fragmented and young movement which lagged behind the main thrust of the disability movement. This is discussed later in section 9 of this chapter, around national issues.

3. What advocacy support-workers should do

This theme reflected the information available as to what the support-worker job role should be, according to the organisation. The following sub-themes were identified:

- Job descriptions and written documentation about groups
- Power given to advocacy support-workers
- Advocacy support-worker views of their task.

Job descriptions and written documentation about the groups

The research revealed the different perspectives of what it was thought advocacy workers **should** do. This was found in the job descriptions and written

documentation about the groups as well as through interviewing advocacy workers and members about their ideas.

Written documentation about the groups varied. For Group A, any members of support staff could use the job description because the role was simply to support the decisions of the management committee. Job descriptions had a tendency to include jargon and were written in small print so they were not directly accessible to members of the management committees (or indeed the Research-team) apart from Group C.

Other job descriptions (Group B and Group D) used language taken directly from local authority job descriptions and used the same pay scales.

One group, (Group C), based the job description around a local authority framework, but described the tasks of the worker as ‘These are the things we want you to do’ along with job descriptions provided in large print.

An overview of the different jobs to be carried out by the support-workers showed the tasks to be widely varied, with some duplication between a senior and ordinary support role (see Table 4). This may have given rise to complications because the senior roles afforded a higher salary than the support role.

THE TASKS OF ADVOCACY SUPPORT WORKERS	
Senior (Management) Role	Support Role
Run the organisation	
Deal with tax, charity and insurance issues	
Find funding	
Assist with Finances	
Develop policy	Develop policy
Develop groups	Develop groups
Organise conferences	Organise conferences
Provide education and training	Provide education and training
	Foster choice and independence
	Make information easy to understand
	Help people speak up
	Occasionally help with personal care

Table 4: The Tasks of Advocacy Support-workers from the job descriptions

Power given to advocacy support-workers

Interestingly, a lot of power was given over to workers in the job descriptions, especially in the senior (management) role. ‘Run the organisation’ implied that support /development workers had the power to determine what exactly the group would do in its everyday running. Yet in contrast to this, documents about the purpose of the groups, annual reports and newsletters pointed to how the groups were, ‘run by the members for the members’, highlighting how it was the members who made decisions, and how the groups were ‘member-led’. This exposed a major contradiction. Additionally, the social model way of working found at Group A, for example, did not set out how to empower members. This was because people who were imposing the social model way of working, rather than members, were making the decisions. Therefore working to the social model,

or describing social model interventions, was far more complex than seen at first glance.

Power and ‘difference’ was also located in the issue around who was paid, and apart from Group A, there were no people with learning difficulties being paid for their work in the offices.

Moreover, because of the lack of accessibility of documentation and the similarities to local authority contracts, it seemed likely that the job descriptions were not actually generated by people within the groups. This suggests that development and support-workers were determining the job descriptions for support staff, rather than the management committees through their members. Yet workers understood the tensions and dangers of doing this on a conscious level:

You know People First always seem to reinvent the wheel, but it's really important that they do that. You have to. When you employ somebody, kind of each group has worked out its own job descriptions and contracts and its own constitution and every group is different. That's a strength really because it's about all those people going through that process. It's part of their personal development. Ian, Group C.

Yet this group, at the same time, handed power over to workers that arguably could have belonged to members. In this group the majority of telephone calls and information coming into the organisation went directly to the development worker in his own office rather than into the main office where members worked. The impact of this system is discussed further on.

There appeared to be a difference between what workers thought should happen and what actually did happen. An important point was to be aware of gaps and conflicts in ways of working, in order to communicate inside the groups about them. Again, this apparently did not always happen:

I think often we are very much focused on getting things done, and maybe not involving members of the group as much as we might. It doesn't get talked about... We have a management committee but they are quite difficult meetings because there is always too much to talk about and they are only once a month. Ian, Group C.

A lot of these constraints were attributed to work that had to be done to fulfil contracts and the pressure of having to constantly seek funding to keep the groups afloat.

Advocacy support-worker views of their task

During interviews, advocacy support-workers were asked to describe their task.

Some comments reflected back to the model people worked from:

Some of it's about changing people's social roles, you get the idea we are in the seventies or eighties, but its taken a while to reach [here]! The way of supporting for me is to help people get regard. I suppose the best thing you can do is drive people to things and all the other bits and pieces of getting people together. One of the best things I can do is get people together so they can communicate and talk about people's own notions of what speaking up is about so it can be shared and understood. Isaac, Group E.

Isaac also mentioned change and how groups of people moved on and developed:

At the beginning there was a lot of learning but in the last few years we've moved away from that to really enjoying each other's

company and debating and acknowledging that some of us know things that others don't know.

This group had been fairly static in its membership although at the time of the research a few more members had joined. The point this worker made is that, in enabling people to get together, members learned from each other and developed their views. This assumed the worker was not an expert but a **facilitator**.

Group B had a more direct approach:

There were requirements for the post; I had to have a teaching certificate so I attended a summer school, Jayne, Group B.

Advocacy workers from Group B taught a number of courses to members with learning difficulties on good communication, assertiveness and other personal development skills in conjunction with the local Workers Educational Association. They had also moved on to a 'Schools Project' where members went into the schools with workers and talked about breaking down barriers and changing attitudes. Jayne claimed that:

Good support is really listening to the members. It is about constantly reinforcing they are the people in control of the organisation. It's about empowering people, treating them with respect and dignity ...

She described her idea of bad support in more detail:

Bad support is doing what you think best and not what is best for the individual, bad support is taking control away from a person.

Significantly, her ideas around support were to do with issues of process, about how things were done, rather than what actually was done. What the tasks were was not clear but her colleague said of this group:

I feel at the moment the job description is really a fraction of what we actually do. Donna, Group B.

Similarly, a different group worker said:

It's 101 things, it's the same for each worker because they are trying to do many People First things so they may be supporting five groups then they will have individuals asking them to support them and the council asking them to do things. So there are like five or six job descriptions each and different jobs that you have to do. It just gets back to you are a voluntary organisation and you have to do everything. You have to juggle all those different things. Gordon, Group D.

Other workers also commented on the amount and diversity of tasks:

- *Ian is overworked and Jackie is left floundering. Cathy, Group C*
- *The more members we get the more people we need to cater for. It can become very difficult because you can't spend enough time with individuals. David, Group A*
- *I do a million things on top of my job... 'Heinz Variety', that's what we call ourselves here! Donna, Group B.*
- *Because we only meet every fortnight it's hard to follow up on things and we have to go back over things. Isaac, Group E.*
- *It's very stretching and demanding. I do worry about Eileen because sometimes she looks very drained and quite ill, because she is on her own doing two groups. Support work is very demanding; we could do with lots of staff. Jackie, Group C.*

Although some specific tasks were mentioned there was a lot of emphasis on how things were done, and process issues were paramount in the thoughts of the workers. It was seen from the job descriptions that a lot of different skills were expected from workers in order to achieve all the different tasks asked of them. These varied from personal care tasks to whole group management issues.

Advocacy support-workers in Group A, who worked directly to the social model, talked about the importance of separating personal assistance tasks from advocacy support tasks as they saw them as very different duties. The manager here also felt that the individual rather than the organisation should employ the support-workers. That would clearly indicate that the individual was then the employer, and had control over their support, so that conflicts between the organisation and the individual's personal needs could be separated.

Other workers, such as those from Group D, felt it was crucial there were core staff supporters employed so that continuity of support to the organisation was possible. **Continuity** was an issue that arose a number of times. Advocacy workers assumed there was an overall lack of continuity in all aspects of life for people they supported:

One of the things I feel about people with learning disabilities is that they do like to have a continuity of support, of people around them, and in some ways it's quite damaging when big change happens. It does happen, people do move on, that's the real world but it's not always a positive thing for people with learning difficulties. Even though you are in danger of getting stale in the way you work, you have to watch out for that. On the whole I think it's better for people to have a longer relationship. Ian, Group C.

What was also interesting here was the support-worker's interchange between the label 'disabilities' and 'difficulty'; a classic debate in the self-advocacy realm (see Chapter 1).

Isaac explained how two volunteers had come to help out with Group E and then swiftly left. I asked if, perhaps, they had not been interested in self-advocacy:

No, it was worse than that. They never came back and explained, they just stopped coming. What I'm saying is they never came back... You find supporters move on and disappear, like a cold thing, that it might be good for their c.v. or something.

In sum, it was found that advocacy workers needed to be a 'master of all trades'. There were many commonalities of types of tasks mentioned but few very specific tasks. Facilitation was a key point. Table 5, overleaf, points out some of the activities workers told us they carried out, in comparison with what the organisation asked of the support-workers. Some of these duties were contradictory and covered a huge range of individual and group tasks, as well as personal and organisational issues. They pointed to a great need for flexibility and skill range of the advocacy worker. It also suggested that the groups needed to be more accurate and specific about the tasks required in terms of contractual issues. Tasks in *italics* describe where the task was found in both sections. This left the bulk of duties undescribed and unacknowledged in the organisations' information:

ACTIVITIES OF ADVOCACY SUPPORT-WORKERS

TASKS OF THE SUPPORT-WORKER OUTLINED BY THE ORGANISATION	TASKS REPORTED BY SUPPORT WORKERS
Run the organisation <i>Develop groups</i> <i>Develop policy</i> <i>Organise conferences</i> <i>Organise and support members</i> Dealing with tax, charity and insurance issues and assisting with finances <i>Finding funding</i> <i>Provide education and training</i> Foster choice and independence <i>Make information easy to understand</i> <i>Occasionally help people with personal care.</i> <i>Help people to speak up</i>	<i>Facilitating individuals and groups</i> Listening <i>Help people speak up</i> Driving people to places <i>Supporting individuals</i> <i>Supporting groups</i> <i>Making information easy to understand</i> <i>Finding funding</i> Counselling Recruiting members <i>Training members in skill development</i> Training other organisations <i>Personal care</i> <i>Organising conferences</i> Attending social events Networking <i>Developing strategic plans</i> Being person centred Campaigning <i>Developing policy</i> Teaching office skills Teaching personal development skills Challenging individuals Being a friend Representing the group on panels Supporting representation Supervising other support-workers Supporting people who are managing the support-worker. First Aid Being available

Table 5: The contrast between contractual and reported tasks of the advocacy support-worker.

4. Advocacy support-workers in action and emerging barriers

This sub-section traces what actually happened during support work and what might have stood in the way of positive support.

The sub-themes listed were put forward by the team as emergent themes during data analysis regarding what had actually happened to workers during the course of their support. Running through all of these themes was the over-arching importance of **access to information**. Each will be considered in turn:

- Members are not included and others are taking control
- The importance of a shared plan and clear communication
- Conflict between the models and views of advocacy support-workers
- Poor quality places to meet and arrangements of space in offices
- Issues of power and empowerment.

Members are not included and others are taking control

Even if the groups had been set up so supporters had no right to a vote, the group infrequently controlled decisions. Indeed the management committees were not standardised as wholly membership-led, in that some of them also included parents and professionals with voting rights. This was the case for Groups A and B.

Often important pieces of information were discussed by workers after members had gone, or at the end of meetings, or when support-workers worked alone in offices.

For example, I asked Yvonne about an event I observed at a management meeting. Members from the local Disability Council had been invited in to oversee that the meetings went in ‘the right direction’ (as per the social model). These two

visitors had tried to persuade Yvonne to agree with their way of thinking, despite what members had said at the meeting about their not needing any more support:

Yes, she was whittering on about how it would give us an extra support-worker in the office – what does that say? You've got a learning difficulty so you are going to need a support-worker so we are going to arrange it for you without asking you about it. We know your needs, I mean, where the fuck is the social model in that...? They maybe will need a support-worker but wouldn't it be decent to ask them? And actually involve them in the process of recruiting them? I think it's awful.

Yvonne, Group A.

This suggested that the visitors from the Council thought they were in a better position to judge what people needed, and further, that their ideas were more important than those of the members. The supporters in this group espoused the language of the social model of disability throughout the organisation, yet there were clearly tensions over how these notions were applied. Yvonne felt people with learning difficulties were under constant threat of being oppressed by other disabled people, implying that a 'hierarchy of disability' was present in the organisation:

I think the mistake in the disabled people's movement is that they have marginalised people with learning difficulties. Now they see that understanding the social model isn't easy to implement. I'm not going to go in and tell people what to do because it's the social model, it has to come from them...so I have to create a culture where people are comfortable and their understanding is heightened. I've got to support the whole organisation to bring them round to a way of thinking that is very abstract.

However, even the idea of 'bringing people round' hinted at an imbalance of power between workers and members.

Importance of a shared plan and clear communication

Perhaps if the social model is to work as a springboard, then people have to be steered towards an understanding of it. Goodley (2000) argued that this understanding was already implicit because people with learning difficulties perceived that they were oppressed. Certainly members talked of 'barriers' that stopped them from being part of society.

Group A supporters did not appear to acknowledge the 'implicit understanding' referred to by Goodley (2000). Yvonne talked about creating the 'right culture' of consciousness-raising, in order to help people explicitly understand social model ideas. Only then, she felt, would actions that implement the social model way of working be able to come from members. It is a daunting task to create a culture in which groups of people are able to make links between their personal experience and the social model of disability. The research showed that teaching and sharing information, at a pace that was right for all members, was required to build that bridge into something explicitly understood, to define what was happening to people from the personal to the political. In short, it appears the social model is something applied by others, not something that arises out of one's own consciousness. It could be suggested this is a key issue of the debate around People First as a political movement.

The backdrop to this full understanding appeared, from the research, to come from people not being included in the thoughts and plans of advocacy support-workers (or others). This stemmed from a **lack of sharing of information**. This appeared to be especially disempowering if it was about the plan of how the organisation

worked. Moira reported how members were not ‘allowed’ to go to a national meeting by their People First group, despite their personal wishes to be on the committee there:

Violet and Trudy are stepping down. In a way they haven’t made the decision, we have decided not to pay. Moira, Group A.

Yet the paradox was that supporters complained about this type of treatment in relation to other people (social workers, family, etc):

You know what people [other professionals] are thinking at the meetings. ‘Oh fucking hell, we don’t want people with learning difficulties here, we just want to get on...’. You can feel it and hear it in the way people talk. Trudy was elected onto the Partnership Board and on the same day her social worker wrote to say she couldn’t have anything to do with People First because of her health needs...It’s ridiculous when Valuing People is about people making their own decisions, it’s offensive. Moira, Group A.

Another barrier that stood in the way of members getting direct information came to the fore:

You get sucked into things you don’t want to as a support-worker. I went on to senior planners’ meetings. I said I would go because they didn’t know how to involve people with learning difficulties. It’s difficult. You have to be careful you don’t get sucked into things as a substitute for people being there themselves. June, Group D.

This could also happen within the self-advocacy groups:

Things are not followed through, even at meetings. Stuff is unexplained; there is a lot of jargon used. There is not the

follow up that there needs to be. Colette, Group C.

An additional example of difficult communication was where things had been said in ways that hid what happened in reality. There were particular phrases that workers used that framed how a group was given information. An example was where George explained to members about some future plans:

We have put in a bid to work in schools. I think the People First idea is that schools have the chance to learn about us. What we are saying is that schools can respect our work and prepare people for the idea of care in the community. That means it will make sense for people to be seen based in the community.
George, Group D.

It could be suggested that if an advocacy support-worker said, ‘What self-advocacy tells us is....’ then **they** had told the members what they thought self-advocacy was. According to the documentation of the group, and the rhetoric of members and workers, these ideas should come from the members. This example, then, taught members about the support-worker view of self-advocacy and perhaps, further, formed the definition of ‘self-advocacy’ within the group. It implied the advocacy worker had a significant influence as they had been in a position to sway the views of others.

Other remarks had been made that were slightly misleading. For example, one of the workers in Group B wanted to bring up a topic for discussion at a meeting. The rules of the meeting allowed only for members to put items on the agenda. She talked about the issue with a People First member before the meeting. At the meeting the worker reported that the member **wanted her** to bring the issue up. The issue had been discussed, but the initiative was with the worker not the

member. Given that advocacy support-workers undisputedly have access to more information, it perhaps would have helped for this process to be transparent and out in the open. If it was known that ideas were coming from support-workers, they could be dealt with as such. Perhaps more importantly is to question why workers go to such lengths to disguise their own input.

These examples showed advocacy support-workers had been acutely aware that issues were ‘supposed’ to be generated from the members. Supporters ensured, albeit by roundabout means, that their own views were expressed in a manner that somehow appeared to ‘fit’ the rules of the group. In order to achieve this they had acted and said things in a certain manner that appeared acceptable. However, they had not always acted exactly as they described to the group.

Conflict between models and views of advocacy support-workers

Interestingly, another theme emerged, that of conflict between the views of advocacy support-workers within the same organisation. Again, this relates to the lack of a shared plan as illustrated by an advocacy support-worker about to leave her post:

Some of the negative things have always been there; I feel my role is not valued. Sometimes I feel like a spare part, I don't think we are informed enough about what is going on, you need to know the core to the periphery or you lose what is going on. We used to have a more identified role and feel more important. Cathy, Group C

Her colleague added:

The development worker is the first point of contact and he takes on a lot of work. He agrees to things rather than bring them

back to the group so there is never that discussion. It's been brought up before but it's not absorbed. Colette, Group C.

Another group supporter also mentioned the difference in the models of support between advocacy support-workers:

We've had a new influx of workers and some of them have been social work students and have developed a style. But people who haven't had this training don't have the same structures in place and are finding it more difficult to grasp what we are about. If somebody doesn't come from that background it's a really different concept of what good support is and isn't, so as we develop it's harder to keep control over what People First is. Gordon, Group D.

Similarly in Group E there had been a contrast of ideology with volunteer supporters:

One or two other people have come along since but they weren't invited by people, you know, they seemed to have a notion about the group as a charity case... Isaac, Group E.

Apart from finding it difficult to sustain continuity in approaches to support and feeling that support was fixed to a group's overall plan, the conflicts could sometimes give rise to severe tensions, where workers could no longer work together. In an example from an interview, where both sides of the situation had been sought, (and in addition the view of members in the next chapter), a worrying state of affairs had developed:

My relationship with David is very poor... We have a really antagonistic relationship. We have different perspectives. He doesn't support, he runs the show, and he has no idea about the power issues. He doesn't help the person he is supporting plan or anything, and I can't get anything done because I just want to

smash his face in. He's the same everywhere; he just takes the piss, just trolls around and does nothing. It's really fucked me off.
Moira, Group A.

I discovered that David's job role had recently been changed so the management committee would be able to dismiss him when the funding for the project he supported ran out, without having to pay him redundancy money. It unfolds in the next chapter that this must have been a support-worker controlled decision through the management committee, because he was actually very popular with the members he worked with, and no-one had complained about him. In an environment where empowerment was held as a crucial concept, these actions appear to be working against the ethos of the organisation. However there were also examples where workers purposefully did not take control of situations, which will be discussed in chapter 8.

The research showed a lot of the problematic support issues could be partly attributed to the absence of a shared plan which everyone had a stake in, so that all knew the aim of the organisation and what they were working toward. It could also be addressed with adequate induction, supervision and training as discussed under the main theme (7) of training and supervision. But some of it was simply about tensions between different personalities of workers as I have just shown.

Poor quality places to meet and arrangements of space in offices

Four of the five groups met in buildings that were quite run down or had access problems. In terms of SRV theory this was an unconscious reminder that people were devalued. It is argued that to reverse the situation (the 'conservative corollary', Wolfensberger 1999), people should meet in modern, well-kept and

attractive offices, which provided for all their personal needs. Groups were conscious that they struggled with the issues of continuing funding (see theme 6), and seemed to ‘make do’ with what they could get. One of the workers from Group C described changes that had taken place:

It was an advocacy initiative based up at Wilson Street. Two of the workers had the foresight to think about what would happen if we got no further funding so the group opened its own bank account and money started going in. We moved to a really tiny office..., and then a big long office, and... then we were able to move into the present office. Jackie, Group C.

Donna from Group B explained that the group had moved to their office due to the bankruptcy of the owner of the previous office. In their new office the first incident they encountered was a flood through the roof over the Christmas and New Year period, which had resulted in much ongoing repair work. Donna wanted to create space for members to use the office but it had a series of steep staircases that made the building inaccessible for a number of the members. They had applied for grants to have a lift put into the building.

Apart from access issues, the research showed another aspect that emerged as significant was the use of space. In some groups support workers occupied separate rooms to members. This, in contrast, was something that could be changed at low cost and which might have positive effects on how an office operated. This issue is discussed further in Chapter 8.

The point again goes back to the importance of information exchange. If members and advocacy support-workers were in separate rooms and not exchanging

information, then outsiders appeared to assume the advocacy support-worker was the first point of contact. This could be prevented from happening if a group had a policy that members always answered the telephone first. However, we did not observe that this happened in any of the groups. As Cathy noted:

There's a hierarchy thing going on, it's there, lack of support, not being informed...Cathy, Group C

Colette agreed:

Ian is the first point of contact if they ask us to do something...to a certain extent a lot of the power is with Ian. People might ask Felix on the phone but then he hands it over to Ian for support.
Colette, Group C.

There were many examples where support-workers attended to jobs. The Research-team felt this had not empowered the members. We had affirmation of this from the fieldnotes, but even in interviews I was told:

Since I've been full time I've been taking on a lot of training opportunities on running an organisation and strategic planning. You need to have a strategic plan before you can have a mission and vision statement. I have been working on my strategic plan. I needed to incorporate targets and so on. Donna, Group B.

In contrast, the view from the group that constantly referred to the social model questioned this type of practice:

When Geoff, a person with learning difficulties got the job, it was David that got sent on training courses about it. What is that about? Yvonne, Group A.

Looking at the use of space in buildings led to the conclusion that if groups had open-plan offices, there would be more likelihood for open communication

happening. Policies could also be put into place about who answered the telephones – that perhaps only members should do those tasks and simply get support when they requested it. Communication could also be improved with regular team meetings and management meetings where everything that happened, including all the letters that arrived at an office, could be read out to all. When we observed who had desk space in the offices it was clear that, in the main, support-workers had allocated desks and members tended to use whichever desk was available. Again, this could be reversed so that members had specific desks and advocacy support-workers went from desk to desk in support of each person.

Overall, there appeared to be confusion about who was doing what job, whether it should or could be a person with a learning difficulty, and what role the worker should play around it. There was little commonality between groups, as Group A appeared to be pushing forward to have people with learning difficulties employed full time into posts. Group D were not contemplating having paid jobs for people with learning difficulties at all. In their group, there had been a bad experience:

We tried it a couple times and actually come a cropper. We had to go to industrial tribunal to get rid of one person. In theory we have worked with that, we tried it, it didn't work out. The person just couldn't do the job and wasn't prepared to take support to do the job. Gordon, Group D.

It appeared that some kind of radical shift would need to occur to open up employment opportunities at Group D. Having employment opportunities within the groups may have quite an impact on power relations, both within the group, between workers and with relationships between the group and the outside world. It may also carry some weight in 'role modelling' (in terms of SRV theory) to

show that it is not beyond the capabilities of individuals to be employed in an equal capacity. However, as indicated in Group A, it may also have the effect of forcing senior supporters to be strict to ensure people do the job.

5. How the process of empowerment worked

This theme was about the complexities of the concept of empowerment. The following sub-themes were identified:

- Being an ally
- Power of individuals versus power of the group
- The see-saw effect of power and empowerment
- Empowerment comes from within.

Being an ally

Advocacy support-workers arguably saw it as their job to position themselves as allies, which enabled people to be heard and therefore challenge oppression in society. The research uncovered a number of positive examples where workers had situated themselves alongside people with learning difficulties. One of the supporters at interview explained:

If it wasn't for People First, members wouldn't have the opportunity to challenge things in their daily lives. For the past 18 months I've worked here I have witnessed the most horrendous treatment of people with learning difficulties that really shouldn't be going on today. The wrong staff are employed in services, there's far too much emphasis on grouping people together in one place so it's easy to control them. I think it's a complete breach of human rights to be put in a workplace and then told you have no other choice but to be there and get paid a pittance or even nothing. To be treated like a child and

told you can't go to the People First group because you have been naughty. I watch that and I think to myself, this should not be happening. Because of this treatment it's quite difficult to establish with some members that they are my boss because they are so used to being pushed around and having no control. I constantly reinforce that they are in control here because I truly believe that is how people are empowered, by having positions of authority. Jayne, Group B.

The references to congregation and valued social roles are a direct link into SRV theory (Wolfensberger 1999), indicating how Jayne viewed what happened around her. There was awareness amongst workers (such as Donna and Jayne from Group B, David from Group A, and Gordon from Group D) of the delicate power issues of support. It was understood how difficult it was on a personal and individual basis, to take up power through self-determination. It was a constant concern to Donna and Jayne, Gordon, Isaac, and Moira, for example, that they may be overstepping their role in situations with members - whether they consciously linked it back to theory or not:

I think it's difficult when you know what somebody is trying to say ~ and you've already been through it, but when it comes to it they find it really hard to get their point across. And in the end you might end up saying something like, Emma is trying to say this... I get that guilty feeling and you think you know it was what they wanted to say but other people maybe think you are putting words in their mouth. I don't try and manipulate - but that is my worry, and sometimes I go away from here thinking - I wish I tried a wee bit harder and prepared so the person could have got that out, because it was important - I feel like I'm sitting on my hands a lot of the time. Gordon, Group D.

Gordon both defended his intervention and questioned it at the same time.

Power of individuals versus power of the group

Power issues were clearly complex and hard to come to terms with. It emerged that the delicate balances made between individuals and how they worked together were far more worrying to advocacy support-workers than what happened on a group level. For example, documentation, policies and business plans seemed to be the domain of advocacy workers and yet the generation and impact of them on members appeared not to be questioned too deeply. It was as if the complexities of working with individuals were easier to notice and reflect upon. However one worker had approached this subject, and explained that although people could develop a voice within an organisation, it was much more problematic when they represented the group on outside organisations:

When you see members of the group at [panel] meetings, a lot of it is about- they want to be liked by those senior managers. Barry was terrible about that, he really wanted to build personal rapport with senior management and to be seen by other members as having a jokey rapport. So he would be really wary of taking a serious issue to a senior manager. You can understand where people are coming from really, the lives they have lived and the institutions they have been in, it gives you authority, if you like, to be on first name terms with senior management, but by doing that you buy into the whole power structure of authorities.
Ian, Group C.

I asked if the group had reflected on this or if it had been discussed in any way. I was told that these issues never seemed to be discussed because there was never enough time, although it was a regret of the worker. In a different group the behaviour of a member representing their group in this way may be interpreted as irresponsible towards the aims of the group. The worker here showed empathy, but was not involved in moving the situation on. The question arose, was that his job, or that of the members who ran the organisation? This confusion and

complexity reached into the heart of the matter – who should be doing what and why?

The see-saw effect of power and empowerment

In terms of power relations, Jayne and Isaac, for example, were wary of group members building dependency and reliance on them. Conversely, in other instances it was seen as important to have continuity in support work so that members could build trust and gain confidence through having some stability, as reported by Ian.

Isaac, aware of his role as a volunteer and that the circumstances in his life might change, said:

Sometimes I think I will walk away from the group and somebody else will pick it up...I would support all of this for any group but I would like to see a point where my role as taxi driver is not that important anymore. Isaac, Group E

In Group A, influenced strongly by the social model, a different approach again was used to attend to issues. It seemed, from the research, that their approach actually carried the possibility of real empowerment in the long run:

The fact of life is we have twelve people here who are responsible for a turnover of £250,000, and they are liable for that money. We have got to support them and train them to be able to do that effectively because otherwise we are the worst kind of people in the world, because we have taken tokenism one step further. So I'm not about protecting people with learning difficulties. It's a big wide world out there and they have to face up to the horrible things in the world...Shit happens. When Geoff asked what the role of the management committee was, not one of them said, 'to manage the organisation' 'I like

being here', 'people are nice', 'I want to help people'. Now I'm really, really sorry but they have got to start taking responsibility for their actions, and I have to create the atmosphere in which they can do that. Yvonne, Group A.

Although the worker clearly led the organisation, her aims were to significantly empower the members. Again this highlighted the complexity of the support issue. The data indicated a see-saw effect to power through the many contradictions and tensions raised.

Empowerment comes from within

Advocacy support-workers who acknowledged the influence of SRV, particularly in Group B, felt that role modelling was of vital importance in empowerment. By this I mean making sure their actions were seen by members as professional and not expressing negative, volatile behaviour (see Jayne's earlier comments).

However, a notion mentioned by most of the workers was that empowerment had to come from the individual, from within. Therefore the work of an advocacy support-worker assisting an individual could only, at most, deal with half of the issue:

We tried to help people to speak out...but that was only half successful because the power lay with the individual themselves. Isaac, Group E.

Workers spoke of the importance of process work and saw empowerment as a lengthy process; 'things take time'. It was clear, that change had to be initiated by people themselves. This change could only occur through issues being understood and through creating the right atmosphere for discussion and understanding. That

was why facilitation was seen as such an important role for the worker. As Yvonne explained:

What I want them to do is that I say something like, well what are we going to do about this? We have a discussion and then someone comes up and says, well hang on a minute, that's not right...and then it's coming from those people and not from me.
Yvonne, Group A

The impression from the intense discussion around power and empowerment, and the tendency for reflection found common to workers, was that they were committed to providing the conditions for empowerment to take place. However, a lack of analysis around structural issues of the groups, such as how the management committees worked and how policy was developed or funding sought, also stood in the way. All of this resulted in difficult issues around members having the confidence and the knowledge to challenge situations. It may be that groups needed to look at what they were doing in their own organisations around power, control and responsibility before any challenge to society could be effective outside.

6. Issues around funding

It was observed and reported that some groups such as Groups B, C and E, were having issues over funding and, particularly in Group B having to work in poor and sometimes inaccessible environments. Four of the groups were funded and had an office base where they worked from, as well as employing advocacy support-workers. Group E did not have funding or an office, even though it had been running for over twelve years. Consequently, there were a lot of different

views about funding from advocacy support-workers. Some thought funding was essential:

My point is that without money it's difficult to create any different type of organising, so it's up to the workers really to support people to get the funding. There's an issue over, who is responsible. Gordon, Group D.

All of the groups, apart from Group D, felt the constant drive for obtaining funding cut across the aims of the groups:

You need a slow pace, Maybe we want to do too much and try too hard. There's money coming in but what is going to happen to People First? Money may be not so important, maybe it's better to have less money but know more about what is going on? Colette, Group C.

Another viewpoint was:

The difficulty with funding is you can chase and chase funding and you eventually lose the plot of what you started out to be. The money ends up dictating what you have to do. Donna, Group B.

In organisations where ideas were supposed to be led by the membership, it was difficult to reconcile how groups could maintain their independence when they were tied into producing outcomes for funders.

According to Isaac of Group E:

In some ways funding is very restrictive in the sense of you applying for funding and it's got to be spent by a certain time. But at the end of the day you're talking about people with

learning difficulties and from time to time it takes a wee bit longer to learn wee things. One of the things that take longer to learn is how to understand what the grants mean and what the money has to be spent on. Restrictions apply, here is £1000, we need to have receipts, and we need to have timescales. Even if you write all this down and it takes six months the membership might not accept it because six months ago things had been in a different place. Six months later now, what's happening to me today in the Adult Centre is what's important. Therefore spending the grant from six months ago isn't all that important.

Isaac's view was that the complications of meeting funding criteria did not fit with the realities of members' lives, where their priorities were felt more acutely on an individual rather than a group basis. He explained a case in point:

For the group I work with what is meaningful is what goes on day to day. It's like Mark; 200 yards from here he picked up a pipe bomb at a shop window and took it off for disarmament. That was a couple of months ago. So we talk about what has happened and other people talk about relatives who have been killed by bombs. People just want to be there and talk and enjoy the time. Isaac, Group E.

This group had been discussing obtaining funding over the twelve years it had been together and a number of attempts had been made. Isaac reported that each time it was decided to apply for funding, the group discussed it at their fortnightly pub meeting and invariably concluded that they did not want things to be changed; then time passed until another attempt. They were currently applying for funds and planned to have an office run by the group members.

Ian from Group C, which had significant funding (and was therefore facing a different set of problems) also mentioned the time factor:

You have to understand the organisation and involve people in it.

If you have a lottery bid you have to find out what the group wants and what for, and how much money, and you have to think about what might be needed. So there's a lot of talking to members and the management committee and all that sort of stuff.
Ian, Group C.

Taking up time was an important consideration in a group because advocacy support-workers reported that they had more work to attend to than time available, yet the process of inclusion was time-consuming by its very nature:

Our funding is due to run out in 12 months time. We need to secure longer term funding again. There are many more demands on us now from our members. They want more training and they want to be here at the office more, so the future is that they will be here really and they will run it. We will help them until they don't need our help anymore. But to do that we have to continue the funding. Donna, Group B.

The research showed it was reportedly hard to illustrate outcomes of empowerment, but more than that it was difficult for members to take control of funding bids, and present them as their own. Not only were the funding forms generally inaccessible, but the administrative challenges of a funding bid determined that members would require a lot of support. Funding also required particular outcomes, which were not necessarily priorities for the members. This implied that funding was a particularly difficult area for group members to take control of.

7. Training and supervision

This theme was about support-workers' views around the necessity (or not), for training and supervision.

Once a support-worker's job began, there was a significant absence of induction and ongoing training as well as (particularly in Group A), regular supervision. This deficit in training was mentioned by workers from all of the four funded groups. The two workers from Group C, on the verge of leaving, both criticised the organisation in this respect. However some workers, such as Jayne from Group B and Gordon from Group D, had come to view lack of training as a necessary situation. They expressed the views that they had come to understand that you learned from the people themselves. In response to my question about what sort of training advocacy support-workers had, came what turned out to be a typical response:

I don't think I got any training. I was very enthusiastic; I didn't see that I needed too many boundaries. Ian, Group C.

However later he made a more negative comment:

There isn't a very strong plan of training, and we haven't really got any. It's been a bit of an issue really, we haven't really done much training.

In another group, although again training had been absent, the support-worker viewed it as a bonus:

I found it really difficult when I first started working with no in depth training. It was very much a case of, right your induction is over, go out there and get on with it. Now I realise why we were put into place in that way, because we all needed to do it our way with the groups rather than be told this is what you do, you do this, and you do that. I think you have to do personal development yourself with the members. Jayne, Group B.

In another interview the worker was cynical of training:

We never had a day of training. We don't do that, we just come

to form our own style. We are working with people, real people, not just clones of some system or something, we don't need a book to tell us this is how we should be treating people.
Gordon, Group D.

However the workers who wanted training felt they had been unsupported in their role:

I felt unsupported in my role, not by the members, they were great, I found the staff were just too busy. Colette, Group C.

Colette added:

I could have done with training on how to deal with volatile people and how to work better as a team and get the dynamics right.

With these very different views about training it was hard to see how groups could make progress on the issue. The Research-team felt that training was imperative for new workers, but that it should involve spending a lot of time with group members learning about their lives and experiences because they were the 'experts' of their own lives. It could be suggested that some amount of training was vital to improve and develop the skills workers required for the post.

Supervision was also a complicated issue. Although most workers received supervision it was supplied by outside agencies or non-disabled management committee members. It had not, in one instance, involved a member with learning difficulties. For the Research-team this was a surprising finding, because in their experience supervision had always been undertaken between a Director with learning difficulties alongside the support of a senior advocacy support-worker.

Some workers in the study, generally senior ones who supervised the advocacy support-workers in the groups they worked for, had not received any supervision whatsoever for themselves, such as George in Group D and Isaac from Group E. Isaac was, in effect, the only person who supported the group he worked with. As supervision provides both a chance to reflect on support as well as be guided and challenged to improve practice, it's absence could be noted as a huge deficit.

8. National issues

This theme was about the perspective workers had around issues to do with a network of groups across the nation and was based on the idea of the possibilities of forming a UK People First.

The third research question around the purpose of the groups involved analysing why a national movement had been so difficult to form over the past twenty years of self-advocacy in the UK. The Scottish and Welsh groups found this slightly amusing as they had their own national groups which had been running very well, in their view, for a number of years. They couldn't really understand why England had 'failed' in that respect. Discussion around a national group had a tendency to focus on the notion of whether People First self-advocacy was a social movement and therefore a national movement. A Scottish worker expressed:

The English have an issue about support
George, Group D.

He had observed at network meetings that English advocacy support-workers made, what he felt were, unwarranted interventions and put forward their views all the time, rather than take a 'back seat' position. Significantly, Groups A, C, D and E had all attended national events and had contact with People First National. All of them were critical about the People First National group's approach to the national issue. These four groups were all of the view that People First National had taken government money indicating that they were the national group speaking for the UK. However, it was felt they had gone about the development of a national group in an imposing and tokenistic manner, for the main purpose of benefiting their own organisation. Gordon had experienced a lot of contact with the national group:

I think there is a power base in London but other groups don't acknowledge that. They haven't been invited in to elect people and so there's a lot of antagonism. We met other People First groups in England that seemed to share that London were acting as spokespeople. We have decided London shouldn't be talking as if they are England.
Gordon, Group D.

Group A were theoretically against the stance People First National had taken:

London are empire builders and are claiming money in our name and other People First groups. The more subtle politics of that have been missed by members who want to get out there on the big public stage. It's not about people with learning difficulties having the power, it's about the London group having power. It's a political minefield. If we work to the social model we don't want to build links where people are working in a different direction or drawing funds away from us. Moira, Group A.

Moira was also critical of another established People First group that had sent out questionnaires to groups but had not explained that they intended to use the

database to obtain funding as a legitimate national group in competition with London:

[The Group] – they don't have any job descriptions working to the social model. The impression they give is different. They sent us things in the post about putting us on a database which I thought was dishonest. ..as it was to be used with the Department of Health to develop a national network. Moira, Group A.

The lack of consultation over national issues was felt so strongly by Group A that the management committee had withdrawn their two representatives from the People First National Committee, despite the fact that the members were still keen to attend. The manager, Yvonne, said that the members had attended as it was a 'free jolly' and had not seriously represented their People First group. The power of the adherence to the social model in this group seemed to override members' wishes, putting the group before individual preferences. I attended the People First National AGM during the same year as the fieldwork where the member from this group stepped down. She explained at the AGM that it was because she was 'too busy with work within my own group.' Thus the real issue was never addressed.

It could be suggested that the idea of a national movement is important if people are to organise together and change the way things are. All five of the groups felt it was more important to have a national co-ordinating body that could disseminate information coming in from all the groups and act as a body that could be identified as the feeding-in point. There was consensus that the national body should not tell other groups what to do, but to inform groups what other people were doing and gather examples of best practice to disseminate. However,

the advocacy support-workers who discussed this also felt the situation of the groups was too fragmented at the moment. No one had an alternative strategy except that Groups D and E reported being keen to have a member elected onto the People First National Committee to try and work on change from within. Group C already had two members on the National Committee who had attempted to take the same approach. In sum, the reported problem with the national issue was that one group had set itself up as a national group rather than a number of groups working together to establish regional democratic representation. The research showed what was wanted was discussion over what should happen as a national way forward.

9. The difference between service advocacy and grass roots advocacy

This theme emerged from the discussions of advocacy support-workers about the tensions around the work they provided for local authorities as requirements of their funding. With the onset of *Valuing People* (2001) and *The Same as You* (2000) funding for self-advocacy had been made available in England and Scotland. The impact of funding for *Fulfilling the Promises* (2003) in Wales was still to be ascertained.

One of the senior supporters informed the Research-team that everything their group did always led back into an objective of the policy document *The Same As You* (2000). In fact the Scottish Executive funded the group. I asked if the new policies had impacted on the work of the groups. This group reported being happy with the way their advocacy had developed, according to the senior worker.

However, it became clear that the group was developing in specific ways tied to the policy, for example their plans for the development of new groups.

One of the English advocacy support-workers, Ian, talked about how the group had managed to obtain funding through *Valuing People* (2001) initiatives and what this had resulted in:

The work we do for them is time consuming and it's a bit like we are being contained and managed. There's a lot of stuff going into the process but not actually giving any power away, it's still all stage managed in my view. I think we need to test the power by taking some radical proposals to the committees like the National Forums and the Taskforce and see what happens... but if you are part of the decision making process then it is hard to complain. Ian, Group C.

Group A was also wary of the *Valuing People* developments:

The national aspect of the groups with Valuing People, it's a different thing, it hasn't come from within. It's a prescribed thing, yet again, about how the self-advocacy movement should evolve according to the Department of Health. Movements evolve, one, because they have external pressure on them and, two, from the internal pressures within them to move in certain directions. I think that is how the People First movement will eventually find itself.

Yvonne, Group A.

Apart from the political aspects of the differences between service advocacy and grassroots advocacy, it was related that there was an inordinate pressure of work coming from these new contracts. David described how inaccessible notes were delivered to group members with little notice before meetings, making their task of representing views on panels and boards difficult in the extreme. Work that had to go into all the local aspects of *Valuing People* (2001), such as people with

learning difficulties being represented on partnership boards, members being elected onto the Regional and National Forum or Taskforce, was said to have taken a lot of time and energy from the groups:

It hugely impacts on the time of the organisation. As a piece of work that is. I mean I was supporting on two areas' Partnership Boards. There's at least one meeting a week plus all the preparation work that goes with it and making sure the person understands it. David, Group A.

Although David had mixed feelings about *Valuing People* (2001), it appeared to him that it offered:

...the first real step forward of a plan of action for how people with learning difficulties could get the full status of any other person living in England, David, Group A.

According to David and Ian, there had been thought to be a conflict of interest in getting involved because the groups were set to campaign about services and would be compromised if taking part in planning them through participating in *Valuing People* (2001) structures.

In addition, the attention given to the service aspects of advocacy through *Valuing People* (2001) work, created a feeling that it was taking away from the 'real' needs of group members. This may well be a major finding about the impact of 'Valuing People' on pre-existing self-advocacy groups:

We have to give so many reports, maybe the funding isn't the important thing...are we taking on the jobs in the best interests of members or to look good for more funding? We need to go back to basics and build up membership again. Colette, Group C.

Groups B and E were not party to aspects of local authority funding in this manner because *Valuing People* (2001) only covered England and *The Same As You* (2000) only covered Scotland. The impact of funding from *Fulfilling the Promises* (2003) was yet to reach the Welsh Group. Whilst the Scottish Group were satisfied that their organisation was being built and strengthened through money from *The Same As You* (2000), tensions and conflicts were experienced by the English groups.

Conclusion

A number of barriers and problems to support work were identified and discussed above. On the whole, advocacy support-workers were very committed to their jobs and managed to find satisfaction from their work. The main points that emerged from the research were that the workers, although enthusiastic and aware of theoretical models to draw upon, were often unsure as to what the organisational plan consisted of. Advocacy support-workers from four of the five groups talked about 'People First philosophy' and although they showed awareness of the social model of disability, they felt that it was a concept too abstract to be shared by members. Therefore they invested in the feelings generated by members around their own experiences and perceptions of the barriers they faced in everyday life.

Where the social model was being used as the main guidance in a group there were severe compromises being made between the personal preferences of individuals in the group, and the organisational direction. It was too early to say whether the group members would become empowered by the work going into the development of the group, or whether they would become oppressed by others'

actions and determination. There was also evidence, especially from Groups C and B, of lack of planning. Even where planning was taking place, there was a deficit of real input by group members into what the plans for the groups should be.

Although all advocacy support-workers mentioned process issues within the groups, they were not so clear as to what their actual tasks were, as seen by Table 4. Groups B, D and C did not have clear job descriptions, because the description did not cover the work they actually did. There was also a fundamental lack of training and supervision available for workers. However there was evidence from the support-workers of a tendency towards reflexivity. They appeared to be challenging themselves despite the lack of outside reference.

The making of a national movement for England had been difficult and was reported to be due to the fragmentation of groups because of their different interpretations of self-advocacy (Group A), and models to which they worked. Groups A and C had not felt included or involved in discussions. Lack of funding had not helped with setting up the networking required for national discussion to take place. The group that had provided a focus for national development was regarded as 'empire building' and not working in the interest of all of the groups. The movement was therefore viewed as being at an early stage of development.

Communication in the groups was viewed as crucial but in practice was problematic. Although communication appeared to be working well on an individual basis through individual support, group communication was more

testing. There were areas that members appeared not to be involved in at all, such as management and funding. This implied that advocacy support-workers were holding more power in the groups than perhaps they needed to or even consciously wanted to.

There was a difference between the self-advocacy work relating to services, under the *Valuing People* (2001) and *The Same As You* (2000) policies, in comparison with grass roots self-advocacy which was a much broader concept. Although these policies have provided some groups with a chance to access funding, the limitations imposed by such contracts were a concern to the groups who found their time, independence and campaigning aspects compromised. There has, to date, been no study on the impact of 'Valuing People' on the self-advocacy 'grassroots' movement.

This chapter has described the findings from the interviews with support-workers about their own perspective of their job role. The next chapter looks at the perspective of group members about the advocacy support role.

CHAPTER 7

THE ROLE OF SUPPORT-WORKERS IN SELF-ADVOCACY GROUPS

Perspectives of Group Members

In this chapter the views of People First members are analysed and discussed. The chapter relates to the second research question, **What are People First members' perspectives of the support-worker role?** This chapter is largely based on the key role of the Research Team in identifying their own questions and methodological styles of research.

The major themes emerging are detailed in the following sections through a chronology, similar to the structure of the previous chapter. This is because the interview questions were similar (although shorter) and so the responses flagged up similar issues, even though the views expressed may have been very different. Each theme identified had sub-themes decided by the Team through the process of analysis (see appendix 10c for a worked example of the approach the team took), which are also discussed. However, as stated, there are some differences in themes and the methods by which information was accessed, and these will be pointed out as the data are worked through.

The People First Members

Following the process used in relation to support-workers, People First members were given pseudonyms to protect their identity and were assured confidentiality

in the treatment of their involvement. Although some members were happy (indeed, asked) to be known by their own name, it would have compromised other members' confidentiality within the group who did not want to be named.

Therefore it was decided to change everyone's name.

There were 24 interviews of members carried out by the Research-team, including myself. I conducted eight of the interviews; five people because they were members of the pilot group where I researched alone, and a further three people for the purposes of comparison, discussed in chapter 9. The data from these three interviews were analysed by the Research-team working together. There were 12 women and 12 men interviewed (see Table 6, overleaf).

The members' interviews were very much shorter than the advocacy support-worker interviews and more information tended to be gathered from group discussions. Therefore the information presented here relates also to other members who were not named on the list, but who, for example, had taken part in groupwork around the role of the support-workers and in observations. Although all of the people included were members, some also had other roles within the groups, such as directors or co-trainers.

In addition to the interviews, I used fieldnotes and the notes from facilitated group discussions as well as photographs that were used as aide memoire in the process of team analysis. I have also drawn on the use of observations and communiograms (see Chapter 5), in observed group discussions, to gather information on participation and communication by group members:

People First member pseudonym	Group	Role in group	Who interviewed
Geoff	A	project worker	R
Gemma	A	member	R
Jake	A	member	R
Bruce	A	member	R
Adam	A	project worker	R
Martha	B	chairperson	A
Charles	B	co-tutor	L
Kathy	B	member	L
Brenda	B	member	M
Ray	C	member	L
Linda	C	chairperson	L
Felix	C	member	L
Kevin	C	member	L
Trudy	D	visitor	R
Emma	D	chairperson	R
Steven	D	member	L
Colin	D	member	A
Clare	E	member	L
Luke	E	chairperson	L
Mark	E	member	L
Jenny	E	member	A
Deirdre	E	member	A
Barbara	E	member	A
Annie	E	member	A

Table 6: Details of the Members of People First

Reminders of the themes to be discussed are set out below:

1. Members’ journeys into their groups
2. Models and theories
3. What members think advocacy support-workers should do
4. Support practice as understood by members and relationships with advocacy support-workers.
5. Views on power and the process of empowerment
6. Members’ views of issues around funding

7. Members' ideas around training and supervision
8. Members' understanding of national issues
9. Do members see a difference between service and grassroots advocacy?

As in the previous chapter, this is followed by a concluding discussion of the members' views.

1. Members' journeys into their groups

This theme was about how members came to have contact with self-advocacy groups and how they viewed their groups. The sub-themes identified were:

- Becoming involved in self-advocacy groups
- Skills people brought to the group
- Satisfaction.

Becoming involved in self-advocacy groups

It appeared, on the whole, that members were encouraged to join groups by other people, generally staff in services they already attended, rather than just turning up to a group on their own. Emma reported that:

One of the staff at the training centre said to me, 'stop sitting on your fucking arse it's time for you to do something'. At that time I thought it was pretty good. I shouldn't have been at the training centre; I was just drinking coffee and smoking all day. I started going to the group and then I got elected onto the Board. I found out there were People First groups all over the world and we decided to be People First. Then I got to be Chair. Emma, Group D.

It's interesting here that Emma made no comment about the way she was spoken to by the staff member, as if this was all perfectly normal.

Similarly Felix said:

*I got told by a staff member. I was up at the day-centre and he said, 'There's an advocacy group', and I said, 'What's that?', and he said, 'People with learning disabilities and all that', and I said 'What the heck are you talking about?' I didn't know nothing about people with learning disabilities or anything else, but he said to me, 'Come along, see what it's like and all that', so I said, 'Right I'll come along'. I found out what it was about, like there was one of the fellas there and they were talking about long term care and I said, 'I've been in long term care, I was in there an awful long time'. I said, 'I've been in three different hospitals'.
Felix, Group C.*

For Felix, going into the group meant meeting people he identified with who had similar experiences.

Another member reflected that:

I joined to help, not just myself but other people with learning difficulties. Steven, Group D.

Sometimes details were harder to get. For example Luke from Group E:

*Lou: Why did you join People First?
Luke: It's about people with learning difficulties.
Lou: Yes, so why did you actually join?
Luke: To speak on their behalf.
Lou: Anything else?
Luke: To help them.*

Interestingly, Luke used words such as 'their' and 'them', which distanced him from other members. This happened again in another interview with Kevin from Group C:

Lou: *Why did you join People First?*

Kevin: *I liked joining. I helped to get involved. You know Anne, she done the minutes and that. I help her to send them out because they needed somebody. I type them up for her.*

And later...

Kevin: *I like to help in People First. Say you had a meeting just gone, they had one last week. They asked me to come down right? And I helped them. I like doing the teas and the coffee and that, and helping them when they have an emergency.*

It was unclear as to whether Kevin saw himself as a member of the group, or whether he regarded himself as a ‘helper’ to the group, and therefore in some senses an outsider of the group or a sort of supporter with more status. It is possible there were gender issues here, as none of the women distanced themselves from the group in such a way, but equally, not all of the men distanced themselves in this way. A larger sample would need to be sought. However there are interesting links here to the material around identity in Chapter 3 (see for example: Sanderson et al, 1997; Tregaskis, 2002), where it is apparent that people labelled with a learning difficulty sometimes chose not to take on board that perception of themselves.

Another member talked about how he went to a small self-advocacy group and then ‘they’ got him to find another one eventually, which implied some kind of support in order to do that. In contrast he used the word ‘we’ when referring to the group:

*We are entitled to things, like able to go to things you want to go to.
Ray, Group C,*

This made clear his own membership of that group.

Charles was the only person who said he attended the group because he was invited by the group itself. The invitation in fact turned out to be from the advocacy support-worker:

I worked for [an advocacy group] already but it got closed down. Then I was put out of work for 5 years. People put my name forward to go on the management group here, to help out, to teach them. When I say here, I mean my job is here in [town], to help people. Charles, Group B.

Skills people bring to the group

In terms of skills it emerged that Kevin saw himself as an excellent tea maker and useful for typing minutes. Other members also saw that they had useful roles in the group, like Charles who considered himself as teaching others. Similarly, one of the women said:

I help people who can't read. Martha, Group B.

Likewise, viewing himself as part of the group, Felix also said:

It's been made so it's only People First what can use it and it's only members what's got learning difficulties. I can do stuff for them, they can come in and we'll talk to the bosses and talk to social services and authorities and psychologists and all that.

Here we evidenced a two-way process where Felix saw himself as part of the group, but also able to help others in the group. This implied having a dual

identity within a self-help group. Another member from Group D shared the same view:

I find it's very important. I know what my rights are as a person with learning difficulties and so I have that knowledge and I can go out and help others in the same position.
Steven, Group D.

Members therefore had a sense of needing to do something for others in a difficult position. Some people were known to have become supporters of groups themselves after being members, as reported by Geoff from Group A. These were findings that Lou from the Research-team intends to follow up in her own research project.

Satisfaction

Most members interviewed expressed satisfaction with their involvement in People First groups and said there were positive consequences for themselves as individuals. Some also compared the groups favourably with the day centres that they attended, as evidenced in Emma's initial comment.

Similarly, Felix explained:

I think it's pulled me out of a hole, it's got me talking to a lot of people. Now it's twenty years up the line I can say what I want to say because I didn't realise...if we said anything we would get a good hiding. I've learned an awful lot, you know? Felix, Group C.

There were many positive comments to be made:

- *We liked it. We are the bosses and we all work together.* Bruce, Group A.
- *We talk about things and bring them forward.* Jake, Group A.

- *I wasn't shy but it brings you out of yourself.* Susan, Group B
- *I love it. I love the group and Donna.* Martha, Group B
- *I find it's very important for friends and things like that.* Ray, Group C.
- *I've had lots of issues and I reckon without People First I wouldn't have been able to cope with most of them.* Ray, Group C.
- *I like getting involved and things.* Kevin, Group C.
- *They help me, good service...*Linda, Group C.
- *It's important because it's made me stronger, I can do things I couldn't do before... People First has made me do new things.* Emma, Group D.
- *I just love it now, speaking up and meeting people, I just like coming here and seeing Isaac and going to places really.* Barbara, Group E.

It appeared to be commonplace for members to be introduced to self-advocacy groups through the assistance of service staff, though this was not ascertained in all the interviews. However people were already placed in other settings such as Adult Training Centres, although some had been able to find work in their groups and leave the Centres such as Geoff, Emma, Patrick, and Ray. This was something they were all very grateful for.

Interestingly, when advocacy workers were interviewed about coming into the job they viewed themselves as coming in to enable and empower other people. What the members related was that they also had a role in enabling, empowering and helping others in the group. Some took this a stage further and viewed themselves as helping other members but not really identifying themselves as part of the group receiving assistance, such as Kevin and Charles. Was this because they did not really see themselves as having a learning difficulty like other people in the group, or did they simply desire a wider role?

The level of satisfaction was very high with members as most people said positive things about their experiences in the groups. This was perhaps self-evident because if they were unhappy with their group there would have been little pressure to attend. As the groups were independent, then people presumably had a choice to be there.

2. Models and theories

This theme related to the implicit and explicit understanding of theories that may underlie support work practice:

- Implicit thinking about models and theories
- Explicit views about models and theories.

Implicit thinking about models and theories

Very few members articulated explicit thoughts about different models and theories that underpinned the groups. We did ask at interview what people felt the aim and future of the group was, which we thought might help uncover people's implicit views of the nature of People First work. Replies to these questions were varied, and fitted a number of sub-themes already defined by the Research-team in their own discussions:

- People with learning difficulties are not believed or trusted
- People are not included and so others are taking control
- People's issues are swept under the carpet and they are not given the same respect

- There are bigger fish to fry.

These will be discussed in turn.

- *People with learning difficulties are not believed or trusted*

Emma explained that since she had been in People First she felt like:

You are actually a person and people believe me and not like when I was younger and they made out I was a liar. The rules of People First are the same as everybody else. To be treated with respect and not get bullied.

Also, Felix said:

I'd been taught if you said anything in front of staff or owt like that you'd get your head bashed in.

The Research-team had discussed, in full, instances in their own lives where people had believed staff instead of themselves or had not trusted that they could do things. They were not surprised to hear these comments coming from others.

- *People are not included and so others are taking control*

Members expressed views about how in the past they were controlled by other people but now they had an opportunity to do something for themselves:

It's about rights. In the past we were locked away.
(Charles, Group B).

People also talked about how they campaigned for issues by contacting MPs, and how they should have rights to employment. In this respect people asked for disability equality:

We need to campaign and get easy access for people who use wheelchairs. Luke, Group E.

Again, the Research-team had their own experiences of lack of access and therefore predicted that members would find issues of access very important.

- *People's issues are swept under the carpet and they are not given the same respect*

The research found that people felt they were not listened to. There had been views expressed that people were not treated with respect and their needs not viewed as important by others. Members said the groups were there to:

...help people get respect.

Stephen, Group D and Gemma, Group A.

- *There are bigger fish to fry*

Joining together, so that people had a stronger voice, was articulated by Felix and Emma:

All of the organisations should interact like all of them down south, up north, pull it all together, I'd like to see it all pulled together because we could make a massive big group of it if we put it all in together. Felix, Group C.

Similarly:

You do things through People First, not on your own. People all over the world should meet up more than once in five years and should go round different groups and see how things happen. Emma, Group D.

Although these members had not said, 'There should be an international movement', or, 'We should adhere to the social model of disability', it was clear

there were views based on an understanding of historical discrimination of people with learning difficulties. There was an implicit understanding that if people joined together they could have a stronger voice. The experiences came from within the groups, from the group members.

Explicit views about models and theories

One member expressed views using the language of social movements:

Since 1984 the People First movement has been spreading out and getting more and more groups...working together for change, that is what the movement is all about...if people want to do direct action then fine, it's up to people what they want to do, they decide the way they want to do it. After all we are self- advocacy and we need to think self-advocacy.
Geoff, Group A.

This following comment by Geoff was perhaps the most telling of all:

If supporters knew it was a movement and a movement for change, then they would know what they needed to do.

In sum, there was an opinion that people were disabled by society and that People First could be a movement for change. This opinion was not articulated as such, rather members used anecdotes of personal experiences and stories about self-advocacy to make the point. This suggested that the ideas nevertheless existed within the membership as Goodley (2000) argued. Advocacy support-workers had thought the concepts were too abstract for members, even though ideas around barriers and discrimination had been present. This evidence showed that some had been thinking about these issues more than advocacy support-workers assumed, certainly Geoff, Emma and Felix had been thinking along those lines. It

was also clear that although ‘People First’ was referred to in explaining self-advocacy, the term ‘People First philosophy’ was not used at all.

3. What members think advocacy support-workers should do

This theme was a mirror image of ‘theme 3’ of the advocacy support-worker perspective, illustrating the views of members about what tasks advocacy support-workers should be undertaking.

There was a lot of response to this question, not only in interviews but in the groups, facilitated by the Research-team. As an example there was a list provided by Group D as to what ‘good’ and ‘bad’ support entailed. It was very similar to lists taken from Group A and Group B during group work.

What was striking, from the members, was the emphasis on individuals’ preferences and needs as opposed to thinking about the continuity and development of the organisation, or indeed any other organisational issues.

Although a few points were mentioned about ‘knowing about People First’ and ‘knowing about rights’, most comments focussed on personal issues and interactions. The members were far more interested in what the supporter would be like as a person than their capacity to help the organisation develop:

GOOD SUPPORT IS....

- Doing the job right
- Telling people what their job is:
- Understanding it is the members who have control
- Not using jargon
- Keeping the agenda small, 'short and sweet'.
- Being a good listener and patient
- Making sure everyone gets a turn and a chance to speak.
- Ensuring one person speaks at a time
- Never using words like: *Mental, Mongol, Handicapped, Retarded, Spastic*
- Never being racist
- Keeping good eye contact
- Paying attention
- Talking to the person direct
- Not talking behind people's backs or on the phone without permission
- Not helping the person till the person says they want help (or watching their communication).
- Knowing that people can change their minds
- Knowing about advocacy
- Knowing about rights of people with disability
- Knowing about People First
- Keeping confidentiality
- Being clear writing things down
- Using pictures
- Being able to use a computer, e mail and internet
- Being able to get on with people
- If possible - knowing how to use a fax machine, franking machine.
- Knowing how to work with money
- Doing clear handwriting
- Working video and TV
- If possible – being able to drive

Table 7: What good support is...by Group D.

The group then worked on the aspects of support they thought were negative.

Again a lot of the information was anecdotal and based on experiences, see Table

8, overleaf:

BAD SUPPORT IS:

- Being unshaven
- Being badly dressed
- Being abusive, slapping or hitting
- Always arriving late or not turning up
- Using jargon words
- Telling people what to do
- Doing everything for you, *'I'll do it'*.
- Running your life
- Not writing things down, *'I can't remember what happened at that meeting'*
- *'I haven't brought it with me'*.
- Being lazy
- Making excuses all the time
- Being on your back
- Nagging people
- Being on the phone all the time
- Always chatting to pals
- Not respecting people
- Being rude
- Being dishonest
- Giving the group a bad reputation
- Saying bad things about People First
- Not keeping confidentiality
- Not passing messages on

Table 8: What bad support is...by Group D.

When advocacy support-workers were asked about what supporters should do, they too mentioned process issues and indeed some of the responses were very similar. There was a lot of emphasis on respect and aspects of power and control. The expectations of what advocacy support-workers should be like, by members, were not so different from the expectations of supporters going into their jobs. The main difference was that support-workers also reported on organisational issues.

4. Support as understood by members, and relationships with advocacy support-workers.

This theme was about how members viewed the level and quality of the support they received in the groups and how they felt about the advocacy support-workers.

When it came to the nature of support, most people had been complimentary:

Bill Riley was a very good supporter. He tried to encourage people in a friendly manner but he didn't force words into people's mouths. He also inspired you and some supporters can do that. Geoff, Group A.

Geoff's interview proved fascinating. He was well known and had been in the self-advocacy movement for 20 years:

I've seen a lot of support-workers. The good ones let people speak for themselves, but may ask a question to encourage people, not put words in their mouth. They also draw and make things accessible for people, when you see a picture it's easier to remember things. Socialising and friendship are really important, it's a bonus, but you need the job set out and you need a job description. Trust is a really important aspect of support and if you can't trust someone then it's not self-advocacy. Trust is paramount in a People First group, if it's not, there will be friction. Respect is the other side. If as a supporter you don't respect people with a learning difficulty then why are you doing the job? Trust, respect, loyalty and friendship, all those make a good supporter, working together. Geoff, Group A.

This response was full of indications of what a supporter's role was. It was very different to more formal roles of work where perhaps the importance of friendship would not be mentioned and where a more professional and objective approach would be taken. What it did highlight was that the role of an advocacy support-worker was more than just 'a job'. This fitted with the advocacy support-worker notion that it was more about a person's value system and beliefs.

Other people's responses to support work were mixed. Some were open-hearted:

I love the group and Donna...We have supports, they are brilliant, Gerald, Susan and Jayne, I love them all. They are great to me, they see I cross the road, nothing is too much trouble. There are no problems, they are wonderful, Martha, Group B.

When Andy further asked if she had ever had an argument with an advocacy support-worker, Martha had responded emphatically:

Never! And I don't intend to. I wouldn't because everything they tell you is for your own good.

This proved a fascinating response. It raised questions over whether the support-worker was advising or telling her what her to do. Perhaps it was simply, as the previous member suggested, about trust. Adam from Group A had told me quite succinctly:

Patience makes good support.

Mark from Group E had confided:

Isaac is very good; he's dedicated to the job, so he is.

More negative views were occasionally expressed. The advocacy support-worker who had a conflict with her colleague, (because she had disapproved of his method of support), was not wholly popular herself. Gemma found her to be difficult:

I don't mean to be strict but she is 50/50. Nice and nasty. She has always been bossy and thinks she is the boss. She doesn't understand the rules of People

First. She hasn't really worked at being a good support; I think she needs to relax a bit. She should try and be Miss Nice Lady, but she has been nasty since I've known her. She is stubborn and bossy. Gemma, Group A.

In contrast, Gemma's view of David, who (unknown to him or her), was going to be made redundant, was:

David is very friendly and understanding. He is always there when you want him; he's helpful and explains everything you need. He'll write it down for you so you have it to keep. He is reliable, he is good as gold.
Gemma, Group A.

It seemed ironic that a group that espoused the social model of disability could have worked against the views of members in such a blatant way. Even if Employment Law issues were guiding the management (through advocacy support-workers), it seemed underhanded to suggest a change to project support status enabling redundancy. Had this been expressed in full to members, it is unlikely they would want to see David leave.

Felix, from Group C, noticed there were influences on the way workers acted:

We have got seven staff what I would say were very truthful, but like all staff they can play up. If they get out of hand they've got to watch out. Watch their p's and q's. But they know who the boss is. It's the members what are the bosses.

Significantly, Colette had said she felt the person with most power in the organisation was Ian, so there was a marked difference of view on this. It raised the question, was Colette more insightful, or was she merely making assumptions?

Lou questioned Felix in more detail about support:

Colette and Cathy, they are good support-workers but they can be a bit wild if you know what I mean [Lou stifles a laugh]. So I kind of put them in that category, but otherwise they are great people. If you split the two of them up they will do the work as much as possible. Felix, Group C.

With an awareness of relationships between advocacy support-workers, members were in a good position to deal with difficult issues that arose over support. We were told that there had been problematic issues in the past and that members had dealt them with. Ray verified that members tried to deal with their issues alone in a separate interview:

If there's a sticky situation in our group, it's better for members to try and cope with it on our own without support. But say if it gets out of hand that's when we usually ask a support-worker. Ray, Group C.

This suggests that members attempted to run the organisation themselves, but felt they had access to back-up when they needed it.

5. Views on power and the process of empowerment

This theme related to the complexities of the concept of empowerment. In the group discussions about support, members had expressed ideas around issues of power. This included the points that workers needed to realise who was in control of the groups and not act in a discriminatory manner. The fact that members mentioned advocacy support-workers should not slap, hit or be abusive was a sad reminder of people's experiences, common to group members. There were not many specific references to power and empowerment throughout the interviews with members but there were references in more embedded ways, such as when

members talked about the changes they wanted to make and the things they wanted to do.

Some of the interviews, where people had found it more difficult to respond to questions, or where we were less able to understand what was being said, revealed an understanding of what the shifts in power were about. Members spoke of the need to be able to:

...speak out.
Jake, Group A

By making sure that:

Members spoke up for themselves. Clare, Group E, and:

I was a bit shy but now I'm knowing what to say. Barbara, Group E.

In some cases the acknowledgement of the difficulty of speaking up was linked to the idea of the advocacy support-worker being able to 'help' in the process:

They help us but they don't take over the meetings. Luke, Group E.

There was a subtle reference to what might potentially happen, but did not happen, because of awareness around power issues. Luke added:

They help you to come here,

thus showing awareness of the knowledge that somebody had to do that in order for the group to meet. On a question about the future of the group, Luke replied:

An office. Get funding as well. And control.

This shows the knowledge and appreciation that power should lie in the hands of the members.

Communiograms (see Chapter 5), used in the group meetings, illustrated networks of who was doing the speaking and how often each person spoke. They were used to look at interactions between members at meetings and to show the impact of facilitation²⁵.

One example was of a management meeting of Group A. It was apparent that most speaking was actually being done between the two advocacy support-workers, followed by the Chairperson, even though there were 13 people sitting around the table. Of these, one person made only two brief interventions, two people made one intervention each, and two people said nothing at all. Questions could be asked as to why the two advocacy support-workers needed to talk to each other at all, and why two people had been left unfacilitated. On a further agenda item, it was clear that people who sat next to the advocacy support-workers were the most likely to be included. Dynamics could change if workers sat out of groups or agreed not to speak to each other.

In a second communiogram, also measuring timing with Group C, there were eight people present at a meeting where three of them were advocacy workers. In looking at a specific agenda item, again most time was taken up by advocacy

²⁵ See Appendix 4 for an overview.

support workers. Two members managed to have two seconds compared to the development worker (80 seconds) and advocacy support-worker (57 seconds). None of the advocacy support-worker interventions were about facilitation of members' views, they were about comments, opinions and ideas expressed by advocacy support-workers.

Empowerment through communication was exceptionally important for members. Not only was it about facilitation, 'they help us to do things', but also around practical skills of making information accessible. One member expressed the view:

I'm not trying to be harsh or nasty but if someone can't understand things it's because the supporter isn't explaining things well, that's why the person can't understand. They need to give back-up and help with things, and also not show off. Gemma, Group A.

Another member, talked about the skills required of an advocacy support-worker and asserted:

They need to draw on an artistical basis while people are talking, they need to be doing symbols and pictures. Geoff, Group A.

Apart from two of the members, most people spoke about the personal interactions they had on a one-to-one basis with advocacy support-workers. This implied that these interactions and experiences were of the greatest importance to group members rather than the group issues relating to the organisation, as mentioned

previously. This was again borne out by the observations of advocacy support-workers.

This situation could cause tension, as shown by the ‘social model’ group, where more global, political issues were regarded as the aim. However this did not mean that ideas could not shift. Members who had been networking with other groups and people seemed to have a much broader view of what self-advocacy groups were (or could be) about, as evidenced by Emma, Gemma, Felix and Geoff.

On a personal level members felt that they could develop. Emma who had become a Chairperson said:

My support-worker, George, pushes me. I think it's a good thing. Even if it seems a lot to do, I can get things done. Before I would say, I can't do this and I can't do that. Emma, Group D.

Other people, like Kevin, spoke of having learned about their rights. For example:

I have a learned a lot from coming here. Felix, Group C.

Power emerged at times as a troubled issue between group members. In Group C there had been a lot of rivalry between three of the longer standing male members, which had resulted in one leaving and one actually being banned from the group because of his ‘outrageous’ behaviour. He no longer ‘allowed’ his girlfriend to attend. This may point to some significant gender issues within People First organisations.

In Group D there were also difficult dilemmas to resolve in supporting members who did not get re-elected into posts, helping them deal with their disappointment and change to a less powerful role within the group. Another issue was how chair-people used power in relation to group members. When Andy asked Martha, a chairperson, how members kept control of the group, she misinterpreted the question as being about her power as chairperson:

When I go to committee I keep control. I won't have them walking about until I tell them. One person speaks at a time and they don't move. I've got more control over them now than I ever had. I really have control over them. Martha, Group B

The issue over setting the scene for empowerment to take place, for confidence to grow, and then to watch the person disempower others, captures the complexity of working effectively in self-advocacy support. Martha's support-worker, Jayne, was interviewed after a group meeting in which we had observed Martha chairing the previous day. Jayne said of the meeting:

I could maybe intercept a little bit more, you know after the meeting, sit down with Martha and say, 'You know we need to be careful, we are all here for the same reason and we are helping to empower people.' We talk about that a lot but maybe we ought to start looking at how we disempower people a bit more. Jayne, Group B.

This example was not isolated. Emma talked about her observations of the members of another People First group when she had attended a recent conference:

People get power with rules. The members were using too many rules. Support-workers have to say, 'Do you think that's right?' or challenge it, but they stayed in the background and didn't

challenge. I've seen that from [Group C], too, where support-workers don't challenge enough. I think there has been a lot of bullying. Emma, Group D.

Support-workers said they continually worried about whether to intervene or stand back. If these examples could be communicated within the groups it would help workers understand more about what it was people wanted from them, which in this case was challenge, reassurance and protection.

A further example of power issues within groups was where the group rejected one of the members, Charles, when he was in the role of trainer, despite the expressed need that people had to be given respect from others. When the advocacy support-worker left the room and asked Charles to take over a training session, nobody in the group wanted to listen to him. He found it impossible to maintain any authority. Later I heard him speaking to the advocacy support-worker and realised he was actually an 'official' co-trainer of the group:

I don't know why you have put me with them, they don't want to listen to me - I could not get them to take any notice.
Charles, Group B.

The support-worker told him that the group really needed people like him to act as a role model, but the incident did not appear to empower Charles. It showed that members were prepared to disempower each other.

Empowerment is clearly complex. It was noticeable through the study that members had a preference to be in the company of, and exchanging conversation with, supporters - over and above colleagues. We can make assumptions as to

why this was the case, but the effect of it was difficult for other members to deal with.

6. Members' views of issues around funding

This theme reflected how much participation members had in applying for and managing funding bids for their groups.

Members reported little information about funding. This may be due to the observations made in the previous section that members had little to do with the process of developing funding bids, and therefore could exercise little control over that area of work. Group C produced very accessible accounts in large print with easy explanations and pictures. Other groups' accounts were difficult both to read and to understand and were simply photocopies of the auditor's end of year accounts. Geoff, who had mentioned funding, wanted it to be given to everyone, not just his own group:

At the moment we don't get a lot of funding but we can support each other to get every group funding so no-one loses out.... everyone describe what you want to do in your area and we will supply the funds and you don't need to struggle anymore.
Geoff, Group A.

Geoff was very keen on organising a national movement. Others mentioned funding in passing:

...to get an office. Luke, Group E, or,

We've got a shortage of money. Charles, Group B, and:

We need to get to the lottery to get more funds and if we don't there

won't be no more People First. We can't do anything now until we know we've got more funds. Martha, Group B.

When members were talked to informally there was not a lot to be said on funding. Group C held a business planning meeting which was observed. Even then, the workers had a great influence over the ideas written into the plan. However, Ian, the development worker, was the only person who actively questioned where the money would come from to allow the ideas and plans to become reality.

7. Members' ideas around training and supervision

This theme related to the apparent lack of training available to advocacy support-workers.

It was noted in the previous section that none of the advocacy support-workers were receiving supervision from group members and therefore none of the members were getting training in the management and supervision of workers. Yet many of the members were directors or trustees of their own companies or charities and were, therefore, legally liable as employers. Geoff's interview contained a lot of dialogue about advocacy workers and their training needs, and was full of empathy:

We want self-advocates to have support and help with shaping the role of supporters. They need to meet every few months and discuss their role and look at good practice. At the moment they have to learn the hard way. There's no qualification, there's nothing out there to support them and it can be a lonely job. Stress levels get really high. Things must start moving to make things happen before we send them to an early grave!
Geoff, Group A.

Members showed that they cared about what happened to advocacy support-workers. The Chair of one group said:

I make sure that supporters should get treated how we would get treated. If you see a support-worker having a hard time, stop and talk. Some of them wouldn't say if they were having a hard time, but if you work with people you get to know them. Emma, Group D.

It was not just one-way. Some training needs were obvious and it was felt that workers should be dealing with them. Emma added:

Some support-workers are in charge and I don't like that. In [town] the support there is pretty shite. [The support-worker] is patronising towards people. I went up there and she was getting people to sit on her knees and calling them little lambs... they are adult! I've seen people sat on people's knees but that's if there are not enough seats.

These examples linked back to the delicate support issues around power. Some issues were subtle and needed to be teased out, but other topics such as the one above, showed a clear lack of guidance and direction from anywhere - to such an extent that the supporter was able to work in an entirely inappropriate manner.

With regular supervision, patronising attitudes could be challenged and people's skills could be developed.

8. Members' understanding of national issues

This theme emerged from members' understandings of what a national movement entailed.

Significantly, it was the longer-standing members, and members from groups involved in regular networking around the country, who saw a vision of a larger scale movement that shifted away from dealing purely with personal issues in the groups. Some people had the luxury of busy networking and perhaps did not realise that organising study visits and exchanges could only be done through the group becoming established and experienced, and not least, having some funds.

Gemma, who had managed to travel extensively in the UK and abroad said:

Some organisations don't go abroad because they don't have the money. Some of us have, that's the two to two tango. Groups should have money. Like for instance Laura. She gets us to all the conferences; I don't know where she gets the money from. Others don't have enough money or enough guts to do it. Gemma, Group A.

Sharing information was important and, if Gemma had known where the money was coming from, it would perhaps enable a better understanding of the situation of other groups.

Emma described their efforts towards establishing a national movement:

There will be a movement if everyone starts to get together. People don't do enough to do it. If there was money and people had time, or gave more time to it, it would work. I think there should be a UK People First. Emma, Group D.

Likewise:

I would like to see a UK People First, a national People First, but not forced onto people. It must be done in a democratic way and no one going out there saying, 'we are setting up a national People First, like it or not'. I'd like to see us debate about it, who is against it, who is for it, a bit like a referendum.

Geoff, Group A.

I'd like to see it all pulled together because we could make a massive big group of it. Felix, Group C.

Felix, Geoff and Emma were well known individuals in the self-advocacy movement and had been networking for years. They had witnessed various attempts to create a national network over the years and bore witness to the ensuing struggle of groups against each other. Each of them said they were open to debate, and were unimpressed with the current national situation. Similar to the advocacy workers, they wanted something to happen, but there was no apparent plan. In the meantime both Emma and Felix talked about membership of the current national People First committee as a place to try and 'make changes from within'.

9. Do members see a difference between service and grassroots advocacy?

This theme traced the members' perspectives of work generated by *Valuing People* (2001) and *The Same As You* (2000) documents.

There was little said by members about the *Valuing People* (2001) and *The Same As You* (2000) documents, despite some of the members having participated in the planning and development, leading up to the writing of each of the documents.

One member noted that:

The National Forum ideas are about what the government likes to see happening, but the self-advocacy movement goes further and wider than that. Maybe it means developing our own services and being more united. Geoff, Group A.

Apart from this, it appeared members were not really that aware or even concerned about what was taking place in terms of their group's representation at panels and on boards. Partly this lack of interest could be explained by the lack of knowledge members had on funding - and therefore on contractual obligations and outcomes the organisations had to meet. By far the more important issues for the members were the way and manner in which things were done, the process of work in People First.

In discussion of national issues with members, the Research-team felt that workers need not worry about planning and having ideas, because there were plenty of ideas coming from the members. According to the written documentation of the organisations, the support-worker role should have been about supporting the plans and ideas of members. The Research-team saw a need for members to be in the forefront with the supporters following behind, rather than the other way round. The team felt that because of the statements advocacy support-workers had made about what they did, they were unclear about their role. This lack of clarity was illustrated by, for example, Yvonne from Group A and her management style; Group D and its adherence to service policy; Donna from Group B with her expressions of ownership; and Ian from Group C, who made important decisions alone and without reference to members.

The Research-team also thought the role was unclear to some members. Martha, for example, had stated how she would not challenge an advocacy support-worker because 'they are right' and similarly Kevin, who expressed he would do what he was asked. There were exceptions such as Felix, Geoff, Emma, Ray, Luke,

Stephen, Gemma and Charles who would challenge advocacy support-workers, and had a view of their own right to take decisions within the groups. The Research-team felt workers need not be concerned about imposing the social model on People First groups, because they thought groups would get to these conclusions themselves, of their own accord, in their own time. The team thought people like Emma, Felix and Geoff were vital in leading such a process forward.

Conclusion

On the surface, members appeared satisfied with their advocacy support-workers and wanted to work together with them to improve support. However, underlying the enthusiastic responses we uncovered a number of issues that needed to be explored.

The members we spoke to appear to come into the groups initially through support from others, but actually remain there through choice. There were some questions over whether members such as Kevin and Charles identified as group members or if they saw themselves as ‘helpers’ and therefore apart from others within the group. Members, like Steven, felt they brought skills of their own to the group. Being in the group was conceived as their ‘work’, which was about learning the skills of self-advocacy. They were then able to use those skills to help others coming into the groups. As a natural development there was evidence of some members going on to become support-workers themselves as reported by Geoff. These people could potentially be very powerful role models. Members in the research were unanimously reporting satisfaction within their groups and some,

including Emma, Steven, Martha, Ray, and Annie, could perceive personal and skill development.

In terms of underlying theory, people such as Felix and Charles were aware of the impact of their past lives and the similar experiences of others, and how discrimination had limited their lives. It was understood that there were barriers that people could overcome. However, this was not expressed by the theoretical concepts of the social model, Social Role Valorisation and People First philosophy, even though the peripheral understandings of those core concepts were present. Individuals had different skills, abilities and level of understanding, but even where communication was difficult (such as with Luke) concepts around power and empowerment were being expressed.

There was substantial focus on process issues with advocacy support-workers and also upon their personalities. Concepts outlined by Geoff such as friendship, trust, respect and loyalty were key to the notion of what made a good advocacy support-worker, and this may well be over and above what is expected of people in other jobs. Familiarity rather than distant professionalism was sought. To this extent members also found these attributes to be more meaningful than the advocacy support-worker ideals around global visions and ideas of a movement.

In terms of communication a number of issues came to the fore. Communiograms showed, albeit as a representation of what was going on at the time, that members could be enabled to speak up and participate more in their groups if rearrangements were made around the dynamics. There was an emphasis placed

on the need for accessible information, reported by Geoff and Gemma amongst others, and the need for workers to be highly skilled in that area of work.

Some members, like Emma and Ray, wanted to be pushed and challenged and would have liked to see workers intervene and protect more readily when group members were bullied and disempowered by others. This implied that members looked towards workers to provide a safer and more comfortable environment.

What was seen as ‘good support’ also tended to be where the advocacy support-worker had minimal impact on what the group was doing but acted as a communicator of information.

The rejection of members such as Charles taking on a support role needed more study to uncover why this should be. Members also needed to have access to more information on management issues within the organisations, in order to be able to take up their legal responsibilities.

Geoff suggested that qualifications should be available for advocacy support-workers but that this process needed to be controlled by members. Members were also looking towards a national movement but one that was set up democratically and moved at its own pace. There were also ideas emerging about self-advocacy group members setting up their own services, perhaps similar to the independent living movement.

This chapter has presented the members’ views about the role of the advocacy support-worker. There were many different themes to consider that were recorded as a mirror image of the views of the support-workers (see Appendix 10b). The

following chapter examines the commonalities and differences between the two perspectives.

CHAPTER 8

DISCUSSION

Perspectives of advocacy support-workers and group members.

This chapter draws together the commonalities, differences and other issues that arose between the advocacy support-workers and group members' perspectives of the support-worker role. This analysis should enable some explanations to be put forward regarding the third main research question: **What light does this shed on the purpose of self- advocacy groups?**

Initially, the main issues are listed. These are then used to facilitate discussion.

The discussion is reflective and explores and contextualises the impact of the topics on current literature and theory (see Chapter 3), in order to develop a more established and grounded perspective of the support role.

During the discussion further data are drawn upon, including: fieldnotes from the Research-team, documentation from the groups and entries from the research journal; all to provide points of triangulation for validity (see Chapter 4).

Commonalities between perspectives

There were some significant areas where advocacy support-workers and members were in agreement. Importantly, everyone was involved in the independent self-advocacy (People First) movement through choice. Both groups had similar basic expectations of what support-workers should do and the qualities of friendship,

trust, respect and loyalty were seen as crucial characteristics for advocacy support-workers to possess. The feeling that support work was ‘more than just a job’ was shared by workers and members. Significantly, a national movement was wanted by workers and members, but only if it was organised to be democratic and open.

Differences between perspectives

The research revealed that advocacy support-workers differed from members in their view of who was in control of the groups. The workers did not consciously appear to be aware of the powerful role members could take on within the management of organisations on a practical level. This effectively excluded members from the crucial decision-making aspects of the organisation, evidenced through observation of their lack of input around policy making and supervision of staff. Support-workers did not discuss the view that members could move on to become advocacy workers themselves. They may not have realised the extent of self-help happening (Goodley, 2000), between the group members, as reported by members of Group C. Perhaps a hidden difference, one certainly not articulated, was that workers interacted with each other during the management and team meetings we observed, in preference to facilitating group members. Overall, as illustrated in Tables 4, 7 and 8; there was little clarity about the extent of the tasks expected to be performed by support-workers.

The research showed that members wanted more focus on accessible information and wanted their workers to be skilled in doing this. They also wanted their supporters to intervene and challenge members more effectively so as to provide a safe and empowering environment. In contrast, there were areas where they

wanted less input from supporters. Members felt they had the good ideas and that the support-workers should follow, not lead. The research also showed that the members had more understanding of disability inequality than workers assumed they had. Members had the memories of their experiences to inform them in the cases of Felix and Charles and had clearly thought about People First as a social movement, illustrated by the comments of Geoff, Felix, Emma and Gemma. The question arose over who actually are the groups representing, whether it is people with learning difficulties per se or simply the individuals who attend.

Further issues emerged from the research that came to the fore as problematic for the groups. They were neither agreements nor disagreements of views, but pointers to barriers to good support work. These included concerns such as the rhetoric of the organisations in comparison with practice; how an office was organised spatially; the lack of focus on dealing with problems that arose in the workplace; the difficulties of dealing with change; the way power issues around management were ignored.

Because of the depth and variation of the commonalities, differences and barriers, the themes have been amalgamated under main headings in order to facilitate discussion:

1. Communication, access to information and inclusion
2. Individual versus the group
3. Models and theories
4. National /social movement

5. Management
6. Support process
7. Power and empowerment
8. Managing change in groups
9. Summary – what light does this shed on the purpose of self-advocacy groups?

1. Communication, access to information and inclusion

One of the overarching themes of the research, which came up under all of the headings, was effective communication, which was a key to members' inclusion (Caldwell, 1996; Townsley, 1998). Communication within groups was problematic, illustrated by advocacy support-worker complaints about their senior staff (Colette, Group C) and members about their advocacy workers (Gemma, Group A and Felix, Group C). This ranged from verbal communication, accessible printed information, through to the passing on of information from advocacy support-workers to members. Despite the awareness of workers of the importance of accessible information and good communication, it was observed that Groups A, B, C and D were having these types of problems.

Group E did not have an office base, but in any case seemed reluctant to develop written material. This may be sensible considering that the members, on the whole, did not easily read or write. The focus of the meetings was based around the members' ideas and explorations, through (accessible) talk. They had resisted, time and again, the enticement of funding applications, because they were unsure that it would be something they really wanted for themselves (see Isaac, Group E,

Chapter 6). Perhaps significantly, this was also the only group that did not have access to government funding sources, but it was possible the impact the group could have on the outside was going to be limited by this approach.

In terms of people being included, Ian explained that although Group C was very good at getting services outside to look at participation and process issues, ironically, it was not always practised inside the self-advocacy organisation:

I think often we are very focussed on getting things done, and maybe not involving members of the group as much as we might. Ian, Group C.

There was a feeling that image was very important to the support-workers, and that certain aspects of the organisation needed to be highlighted to those on the outside.

It was also found in Groups B and D that workers represented the organisations on outside bodies, rather than people with learning difficulties being supported to do this. In terms of the social model of disability, it implied a lack of participation; ‘nothing about us without us’ (Aspis, 2002), and a lack of commitment on the part of organisations to be inclusive of disabled people. It could be suggested it would create a circular problem because if people do not represent themselves then they will not get the opportunity to learn how to do so through experience.

In looking at the interviews from Group C, as a whole, all the workers understood there were issues regarding lack of communication as well as lack of time in the office and in their work. Similarly in Group A, Yvonne expressed the view that

the management committee members were unaware of their role through lack of training and the passing on of information. Communication, participation and passing of information were affected by:

- *Who answered the telephone in offices.*
- *Who opened the post.*
- *How information was passed on.*
- *Who had a desk of their own.*
- *The accessibility of documents.*
- *How business plans were put together.*
- *Who represented the group with outside agencies.*

The Research-team used this checklist in each group office (see Chapter 5). In all four offices advocacy support-workers answered the telephones, in the main. At times in Group C's office, a member answered them, but, when we observed, this was minimal, as members were involved in other activities. Group D was so keen that workers answered the telephone that Lou was told not to answer it when she was merely looking at the phone. The only exception at this office was for the Chairperson, Emma, who was expected to answer the telephone when she was in the building.

Group B had a worker whose specific job was to answer the telephone and redirect calls. However, few calls were passed to members. In Group A's office, a group member answered not one call when I was acting as an observer.

The very same dynamic applied when letters arrived at the offices. Given that workers spent far more time in the offices than members it was inevitable that

information was going to advocacy support-workers first. Similarly, other organisations phoned and asked to speak to workers rather than members. It was clear from the interviews at Group C that the development worker agreed to undertake work without discussing the requests with the management committee or members first.

Clearly then the impact of information not going direct to members and then crucially not being shared, led to barriers to inclusion, and prevented members taking control of what happened in the organisation.

In addition to the above, the organisation of space in offices held a direct relationship to how much information and participation was available to members.

At Group C office:

There was a larger meeting room and an adjoining mid-size office on one corridor and then Ian and Jackie's separate rooms on the lower corridor...Most activity happens in the meeting room and office, Jackie and Ian's rooms are for their quiet work. Ian commented it was unfortunate how it had developed that way – but it had. Rohhss fieldnotes (16/04/02)

There were separate offices for support-workers in Groups A, B, C and D and apart from Group A, workers had allocated desks, whereas members did not. This meant that the organisations portrayed the importance and permanence of the support-worker role over and above that of its members. It was self-evident because it was only Group A office that employed people with learning difficulties on full wages. However Groups B and C did encourage people to work in the office in a voluntary capacity.

There were also issues of physical inaccessibility, which again resulted in lack of participation. This is an excerpt from Andy's dictated fieldnotes about Group B office, where he was restricted to the ground floor space for his fieldwork:

In the People First office I liked the kitchen, but the sink was too high. No one disabled could wash dishes at the sink. The doors... (turns to Malc) you said you didn't like the handles. There wasn't enough room to turn....I would say though that it is hard to get around corners because the doors are in the way and it is not very wide. It needs to be made more accessible. That is one thing they could do better. The toilets too are not very good to get into and use, I wouldn't be happy working there like that.
Andy's fieldnotes (21/05/02)

Lou added:

The fire doors are very big and heavy, it would really hurt if one of them smacked you in the face. Lou's fieldnotes (21/05/02)

Likewise in Malc's notes:

We had a look around the office, bits of it wasn't very appetising, it was spread all over like the filing stuff wasn't in a proper filing system...Malc's fieldnotes, (21/05/02).

I observed that the doors were not just making the building inaccessible, they were actually dangerous:

Coming back from the interview on his own, Andy's chair got caught by the fire door and hot coffee flew all over him. The doors are heavy. There are four from the back training room to the front room. If there was a fire people could not save themselves, they would actually be obstructed from leaving by the doors. This means the fire safety rules are built on the dependency rather than the independence of disabled people using wheelchairs in the building. Rohhss's fieldnotes (21/05/02)

The question was raised in Chapter 3, following identified gaps in the literature, as to whether there may be a tendency for workers to (albeit unconsciously) neglect to challenge dependency in order to have a useful role. If issues of accessibility were left unchallenged, as evidenced by the research, then supporters could be seen to be perpetuating dependency.

It was not just about the physical office space, there were other facets of inaccessibility. The Research-team found that much of the groups' information was presented in small print, so they could not look thoroughly at the documentation we had asked to see. The team found this frustrating and reflected on what that meant for group members.

The team also reflected on why the training courses at Group B involved the keeping of files (which relied on the written word), when it was known that members were unable to read or write. Everything from the Group B session I had observed (ironically, on the importance of communication) was written onto flipcharts with no pictures. Later Donna said that no one in the group could read or write but the Workers Educational Association insisted on this written proof for moderation purposes. She explained that each person therefore had a file.

As Ruth Townsley (1998, p.77) observed, 'Information is power':

For the majority of people with learning difficulties, a society that relies on printed information is a society that excludes them...having access to information in an understandable form is something that is integral to any notion of empowerment or self-advocacy...Access to information in appropriate formats is a human rights issue.

This was not just a feature of Group B. The only group that had made particular efforts towards writing their own accessible organisational documentation was Group C.

There was also an issue over information not being shared or passed on. An instance observed at Group D showed that even the organisational plan had not been shared amongst the members, or indeed the advocacy support-workers:

Fraser, one of the People First members from a local group stood up and proudly reported that their group had been successful in a long process of getting money out of the local council to pay for part time support. He was heartily congratulated by other members around the table....George, who was a senior support-worker, was frowning throughout his report and then got up to speak: He said, 'You'll notice I'm not jumping up and down for joy...'. He said that the local groups should leave any funding issues to him and the person he supported, because they would argue for more money and more workers in wider areas. He said that the council would now feel by granting a part-time worker they had done enough, and the opportunity for more funding would be lost by the local group's action. Fraser, who had been talking proudly of his achievement looked crushed but said nothing. No further discussion was had.

When Gordon, the supporter of the local group arrived late, he asked if Fraser had reported on the funding being gained. He said, 'Wasn't it a great piece of news?', reinforcing the actions of Fraser and in total contrast to the senior support-worker, George. Rohhss's fieldnotes (19/06/02)

This example showed a number of problematic advocacy support-worker issues coming together: the lack of a shared plan, the lack of sharing and pooling information, the ease with which comments disempower a person, and the needs of the organisation being put above individual needs.

All of these aspects came together in the running of a self-advocacy group and needed to be critically reflected upon. Being a member of any group was difficult

when workers, or those who take over leadership, were controlling information. Sometimes there were issues around confidentiality, so their supporters did not tell the directors or members. But sometimes it was not simply a question of control, where an advocacy support-worker was withholding information. The research showed that for all the groups a co-ordinated plan was missing, one that was owned by all of the parties in the group, which enabled everyone to know what their task was, and where their task fitted in the 'big picture' of what the organisation was striving towards.

In contrast, there were some examples where information had been taken seriously and was acted upon:

At a meeting about 'keeping control of the organisation', one of the members needed to leave the room for a short while. Jayne stopped the meeting and people chatted until the person returned. This meant that none of the information had been missed and everyone knew what was going on. Rohhss fieldnotes (19/03/02).

The research revealed that communication and accessible documentation were crucial to empowerment. There was an overriding (and seemingly unacknowledged) problem over creating and perpetuating dependency, where issues of access were not identified, and changed. The groups were alert on a superficial level to these concerns, as reported by Ian of Group C, but had found it a challenge to put theory into practice within their own organisations, most particularly at an administrative and management level. Perhaps this explained

why none of the members suggested their workers could move on and leave them to organise themselves.²⁶

However, there may be another way of thinking about the relationship between advocacy support-workers and members. The research showed that Group A had tackled this problem, though Group D had no intention of doing so. Rather than a dichotomy of role, perhaps the natural development of the groups would be for the workers and members to be working in ‘partnership’. This was a role suggested by Wilson (1997), and evidenced in Group A, where people with learning difficulties were taking on a fully employed role. However the research was carried out when this change had only just been made, so it was hard to ascertain the impact on the organisation. Additionally, in Group A, the everyday management of the organisation was carried out by people senior to any worker with a learning difficulty, and thus still had more control over what happened in the organisation.

Although the groups showed understanding of the imperative access to information issues, it was not a thorough and holistic understanding throughout the whole organisation. Group B felt obliged through their contract with the Workers Educational Association to carry out an inaccessible process of recording. However, in addition their other documentation was inaccessible. There appeared to be a kind of ‘glass ceiling’ around management issues, making it difficult for people to compete for power in their organisations against literate and knowledge-holding supporters. This is a feature common to many other

²⁶ This was a suggestion for a future study made by Dan Goodley (2000), to ascertain the viability

organisations often cited in feminist literature about the difficulties women encounter on moving up through the [male dominated] hierarchy of work (Sneider, 2000).

Accessible communication was a pivotal issue for people with the label of learning difficulties. As well as ramps, aids and adaptations, accessible information was the bridge for people into participation (Chapman and McNulty, 2004; Walmsley and Johnson, 2003). In the list generated by members of groups, about what they thought workers should do in terms of communication (Chapter 7), we were told they should:

- Be clear writing things down
- Use pictures
- Be a good listener and be patient
- Talk to the person directly
- Don't talk behind people's backs or on the phone without permission
- Don't help the person till the person says they want help (or watch their communication).
- Keep good eye contact.

It was seen as bad support not to pass messages. As Gemma from Group A remarked:

If someone can't understand things it's because the supporter isn't explaining things well... They need to give back-up and help with things.

of advocacy support-workers working themselves out of a job- something that had been suggested

Gemma's comment suggested accountability was placed firmly on the advocacy support-worker to act as a translator, thus completely circumventing any impairment issue of the individual. This was a significant finding, because it suggested a clear perception of the support-worker role and the responsibility the worker needed to be taking, couched (albeit unconsciously) in the social model of disability. It was also a denial that impairment gets in the way. This raises further questions over whether there are limits to what even the best support-worker could help a person achieve due to impairments. To take Gemma's view to its logical conclusion, dealing with the impairment is the support-worker's task. As all needs are individual, this idea has far-reaching implications for the number of supporters that may need to be involved in a group.

2. Individuals versus the group

Another linked and overriding theme for advocacy support-workers was the tension between supporting individuals and supporting the group (Chapter 6). The dilemma was that individuals needed to be supported on a one-to-one basis quite extensively but providing the support was contingent on time and funding pressures of the organisation. On a theoretical level this dilemma pointed to the difference between the support approaches to individual and group advocacy.

The research showed that different approaches to support were hard to separate in the everyday running of a group, and types (and underlying theories) of support would change back and forth throughout a day, with different individuals, with varying needs. Indeed the outline of this mix of tasks was present within the job

by earlier writers on the advocacy support role, such as Dowson and Whittaker (1993).

descriptions. However, David explained that as Group A took on more work under the 'Valuing People' policy, the capacity to work with individuals suffered. This was also reported to be happening at Group C.

There were times when what an individual wanted to do (self-determination), would conflict with an overall group aim, as in the example of the two members being told that Group A would not allow them to remain on the People First National committee. Violet had stepped down, as she was requested, but she was not at all happy about it, as evidenced when I spoke to her at the office. During a general meeting she had repeatedly made references to the other people she knew on the National Committee and how they could come and be helpful to the group:

Violet had her mobile phone switched on as she was expecting a call from Natalie at People First National. She had been told by Group A she could not be a group representative as they would not pay her expenses and provide support. She told me she had decided it was such a hassle that she would resign although she enjoys the National Committee. She said that Moira had told her this, and that Moira was bossy. She felt Moira had made the decision and Violet was not happy about it.
Rohhss fieldnotes (16/01/02)

Interestingly, the practical details did not match. People First National provided travel and accommodation expenses in addition to support expenses. This implied there must have been covert reasons for the decision that was made.

If self-advocacy groups are about self-determination (Sutcliffe and Simons, 1993), then having decisions imposed about what individuals can and cannot do clearly does not 'fit'. The impression one was left with at Group A, was that the

supporters had engineered the decision in, what they thought, was the ‘best interest’ of the group.

Ironically, the notion of ‘best interest’ was at the heart of a major campaign by the self-advocacy groups at the time of the research. This was led by People First National and other groups, rejecting ideas in the Mental Capacity Bill that other people (general authority) can make decisions in a person’s ‘best interest’ (forthcoming ‘Mental Capacity Bill’, 2005). So, while People First groups campaigned against others being able to make decisions in the person’s ‘best interest’, the group A support-workers, in this example, were doing just that, on behalf of the members.

Self-determination within the self-advocacy groups was therefore laden with tensions and contradictions. There were many instances observed during the fieldwork where members’ personal problems could be supported by workers, who then helped move those into public issues, thus making the connection in the group between the individual and the organisation, the private and the public.

Alternatively, some people (for example, Geoff, Emma and Felix) had already concentrated their efforts on leadership within the groups; a detail that emerged through the research, where workers had not really taken on the implication of members becoming supporters and leaders. It could be suggested that people like Geoff, Emma and Felix were the ‘second wave’ of ‘champions’ (see Chapter 2); but this time it was people with learning difficulties who provided a role model for their colleagues.

In sum, the research pointed out that supporting individuals could at times conflict with supporting a group, but this issue did not appear to be consciously explored as a problem by advocacy support-workers. David (Group A) had mentioned resource limitations and how that impinged on providing the amount of time needed to give members effective support. The implication is that discrimination will occur, particularly for people with higher support needs within the groups. It is therefore arguably a topic that needs to be highlighted and discussed within the groups.

3. Models and Theories

SRV and the Social model

What the review of current literature did not reveal was whether workers used any consistent theory as the basis of their support, nor indeed whether theory was important to them at all (see Chapter 3). The research discovered that advocacy workers generally worked to some kind of disability inequality agenda (Chapter 6), and that members, although mostly implicitly, but at times explicitly, also worked to particular theories (Chapter 7). This was based on evidence from interviews with workers and members, and at times backed up by observation of conversations, teaching sessions or written documentation. Group A worked explicitly to the social model of disability, as Group B worked explicitly to an SRV model. In both groups these theories were regularly and unambiguously referred to. Gordon and George from Group D and Isaac from Group E made passing reference to SRV theory. Interestingly these models were not openly discussed at Group C. However all of the groups' supporters (apart from A, where

it was only members) talked about the 'People First' way of doing things, as if it was a concept, philosophy or model in its own right.

The rigid application of the social model, expressed by supporters of Group A, called into question the conflict between self-determination of group members and having the social model 'applied' to their organisation. This interpretation of the social model conflicted with the very basic tenets within the social model of 'nothing about us without us' (Aspis, 2002), and of people taking control for themselves. There was however a question to be raised over whether the ends justify the means. That is, if a group were to arrive at an understanding and application of the social model, did they have to be guided and cajoled into it, 'for their own good', as implied by Yvonne (Group A)?

This question was particularly about power, as it queried who was in control of the self-advocacy groups. Clearly, in Group A, it was the supporters. It needs to be ascertained as to whether this is a flaw in the social model, in relation to people with learning difficulties, or if it is a mistaken interpretation of its application, or indeed both.

Yvonne from Group A, drew attention to the 'hierarchy of disability'; where she believed the disability movement had not properly taken into account the position of people with learning difficulties. There was observational evidence that the supporters from the British Council of Disabled People (that Group A were working with) had influenced Yvonne away from what group members asked for, to what the Council supporters felt was 'best' (for their own good).

Andrew Lee, (2003b) Director of People First National remarked at their AGM:

People First, believes in the social model of disability. This means society is the problem, not people with learning difficulties and society has to change. In 1994 I joined my local People First group it was like being part of a political and personal revolution, going out on to the streets to challenge the Government of the day on laws that discriminate against disabled people. It is hard to put into words the strength you get from you and friends standing together and saying we want change and we want it now.

Here again, an individual talked about ‘what we believe in’, similar to the advocacy support-worker, George, who told the group ‘what People First is saying’. As reported in Chapter 3, current literature left many questions unanswered around whether supporters framed the needs of people with learning difficulties. Moreover, it could be argued that framing people’s needs may potentially lead to framing people’s identities.

The evidence from this study suggests that some members had framed their own identity in terms of consciousness of their own disability and movement. They expressed and theorised their own position. However, they were individuals who had been involved in People First for a long time (Geoff, Gemma, Felix and Emma), had networked around the country and worked with other groups. For this understanding of personal identity to happen and shape itself in a person’s consciousness, there evidently has to be time, sharing and an appreciation of the relative position of other individuals and groups through a person’s own experience.

Applying the social model of disability from an advocacy support-worker's perspective within a group, where individuals were perhaps new to the group or had not experienced the ideas for themselves, it is suggested would be especially difficult for people to understand. It is evident from the literature, that for many people, abstract thought (Atkinson and Williams, 1990) rather than experiential learning (Rogers, 1961), is particularly complex. Ian (Group C) had commented about the social model of disability:

I think people have found it hard to get their heads round it to be honest...I think people here feel there are barriers...

The concepts and ideas of the social model and indeed SRV are abstract, require conjecture, and are therefore difficult to comprehend and understand.

However, the theories of the social model and SRV were clearly useful tools, especially in the minds of workers from Groups A and B. Nevertheless, the research discovered that theory was imposed rather than worked through and understood, based on the members' individual needs and requirements. Only in Group A had supporters said that the work of the advocacy support-worker was to enable an environment for consciousness-raising. Conversely, members articulated that they did not need to be led by support-workers; they would reach where they were going at their own pace (Felix, Group C; Luke, Group E). If the groups were to be part of a social movement, individual consciousness and motivation was an inevitable requirement (Bersani, 1988; Della Porter and Diani, 1999; Dowse, 2001). The conflict was this: if the advocacy workers were consciousness-raising then who was in control of the groups? How did group

members and support-workers operate together to achieve the aims of the groups, without the workers taking more power? If a teaching/ learning model was required it could be suggested that it would be difficult to locate and maintain power within the membership. As identified in Chapter 3, through previous literature, the social model, although useful, has not quite centred on the core needs and capabilities of people with learning difficulties. The research suggested another model of understanding.

A People First Model

Advocacy support-workers rather than members referred to the People First philosophy within the research, but it could perhaps help provide answers to some of the questions raised above. As noted before in the previous chapters, the People First philosophy, in highlighting 'barriers' to empowerment and equality, may be another less abstract way of referring to the 'social model' (Goodley, 2000).

There were other challenges to the traditional social model as well, such as the necessity for accessible information and the imperative not to rely on abstract concepts. Research with members revealed much emphasis placed on **process**, which confirmed a view found also within the wider literature. Also of importance was the role **experience** had played in the (largely unnoticed) theorising by people with learning difficulties (Chapman and McNulty, 2004). Throughout the research this point presented itself over and over again. For example, Andy reflected on how the office space at Group B would not work for

him, as he imagined himself being there (i.e. he imagined the experience). Also, Felix (Group C) in recalling his first meeting, explained how he listened to a man who had been in long-term care, thereby mirroring his own experience, and therefore found the group was a place he wanted to go back to:

...and I said, I've been in long term care, I was in there an awful long time. I said I've been in three different hospitals.

'People First philosophy' has not been defined in previous literature; apart from its mention in the Northwest study (Chapman, 1997). The research with members revealed this was precisely the point. Why would it be defined in an inaccessible format, if it was a reflection of the knowledge, process and experiences people have come to in their own way, and sometimes within their own groups? For People First members, writing ideas down and defining them, is not the uppermost imperative.

This did not stop those involved on the periphery making comments and having opinions about what constitutes People First. However the opinions that emerged from the research that defined a 'People First' model were very much more at the forefront of supporters' minds, rather than members. Members were more involved in 'doing' than concerning themselves with written documentation or theoretical models.

The research on advocacy support-workers showed that there was a tacit or everyday understanding shared amongst supporters and members about what

‘People First’ essentially was. A list was compiled (Fig. 2) of comments from the interviews that described the facets of ‘People First’:

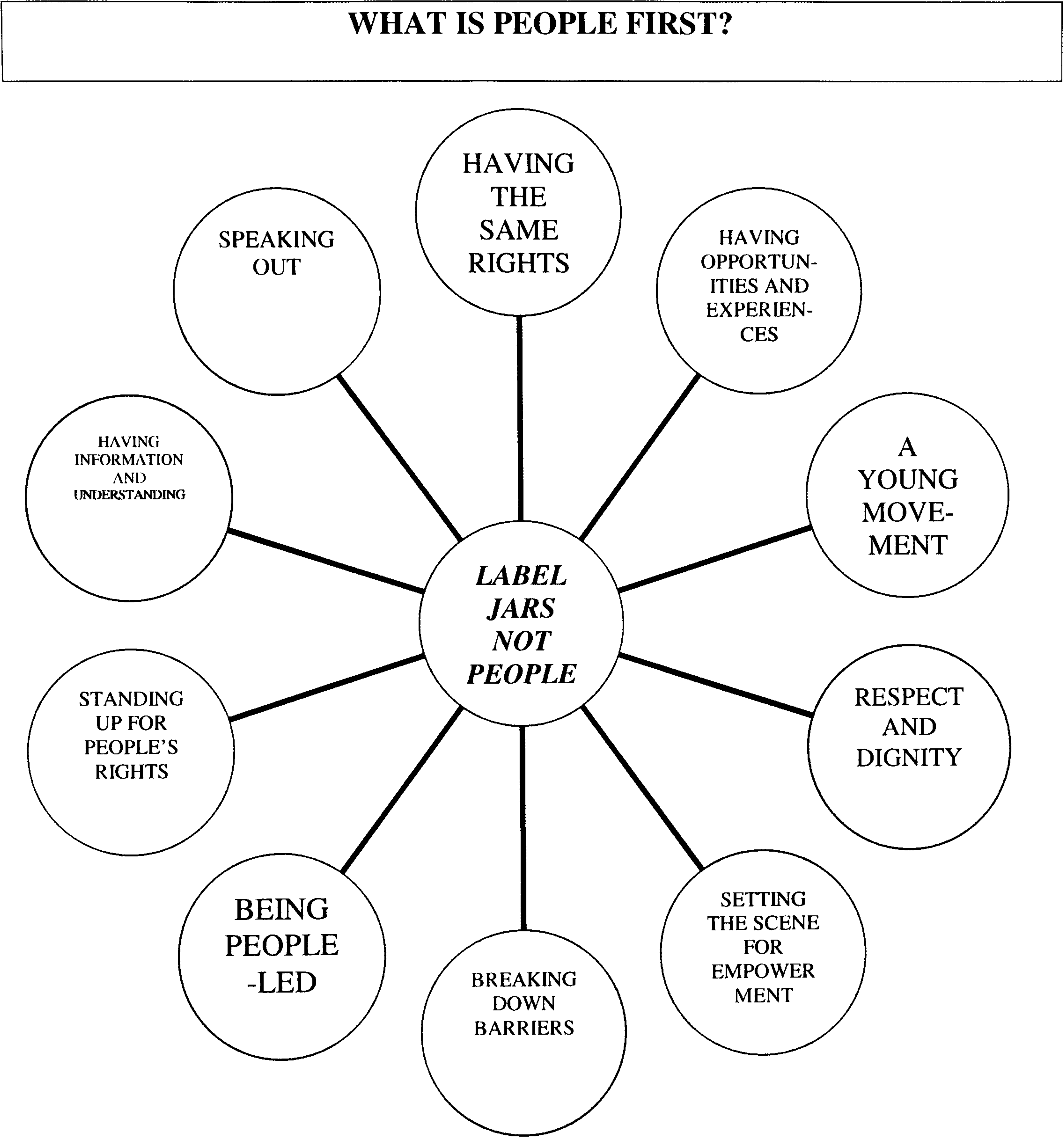


Fig. 2: What is People First?

The centre of the diagram shows the slogan of People First: ‘Label Jars Not People’. Many of the themes on the hub are around the need to be treated as anyone else would expect to be treated, (rights, dignity, and respect). Some of the

themes are around matters that people feel should happen, ('people-led, having information and understanding, speaking out'). 'Breaking down barriers' and the ideas of a 'movement' link the People First model into the social model of disability.

From this diagram it is clear that the research showed People First claims that were comparable with those made under the social model. However, crucially there was no comparable claim that people were disabled (made to have learning difficulties) by society (Barnes, 1991; Oliver, 1999).

The People First model both accepts the impairment issue (by not saying people are made the way they are through societal barriers alone), and rejects it (label jars not people). This implies that labelling is rejected but the impairment issue is accepted. However, the emphasis on process and action in 'the People First way of things' (Gordon, Group D), helps people focus on the access issues around challenging barriers. In addition, Gemma (Group A) felt that impairment barriers were the task of the support-worker to counteract.

The research findings on process point out a distinction from the current understanding of the social model. Both action and process were key ideas that emerged from the research. The diagram overleaf (Fig.3) illustrates the main features of the argument:

The research showed that action and process were of particular importance to members in the study. Because of the difficulty of thinking through abstract

concepts, experiential learning and expertise came to the fore as the tools of People First, mirroring the emphasis that has been placed on understanding people’s lives (and enabling ownership) through life history work (Atkinson, McCarthy et al, 2000; Rolph, 2000).

ACTION AND PROCESS OF PEOPLE FIRST

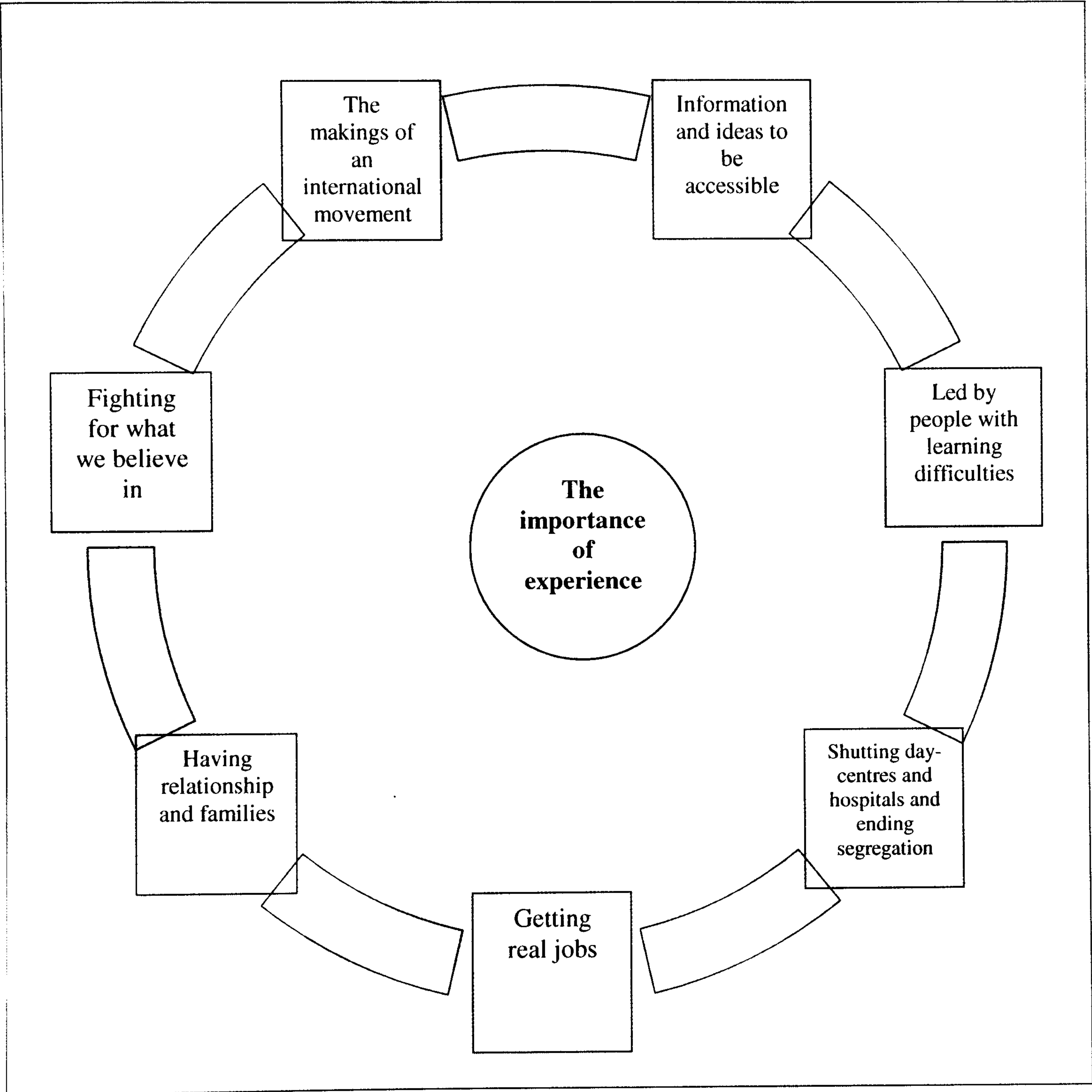


Fig. 3: Action and Process of People First

Additionally, the point was made by Ian (Group C), about the necessity to ‘keep re-inventing the wheel’, (hence the wheel shape) precisely so that experiences

were happening for individuals and they were not having other people's ideas and experiences imposed upon them without understanding what they meant for themselves.

Starting at the top of the cycle, the research showed that, to members, the most important feature in process was the need for accessible information. If people had information and knowledge, it was easier for them to understand how things worked and therefore to take some control. If people were said to be in control but did not have the information required, (as described in Group A regarding the management committee), then the organisation was not led by people with learning difficulties. The next three issues in the cycle were about things that people labelled as having learning difficulties wanted for themselves, which they were often denied. These issues were regularly discussed in the groups. If people had the opportunity of real jobs and real relationships where they could become parents, then there would be no need for the segregated day centres and hospitals which kept people away from doing ordinary things. The last two points on the cycle were about the joining together and sharing of experiences. The research showed this was crucial if groups were to work collaboratively (as described by Emma, Geoff and Felix). The centre of Fig. 3 was the key area of personal experience.

None of these features stand opposed to the social model of disability, but there was more emphasis in the research on the need to address issues of impairment through experiential learning so people could understand processes. The research also highlighted the need to make information and ideas accessible. Everyday

assumptions, borne out by the interviews with group members, indicated there was still, at the present time, an essential role for allies and supporters who do not share the label of learning difficulty (Chappell, 1999).

In sum, the research has shown that advocacy support-workers generally work to some kind of disability inequality agenda, usually voiced in terms of the social model or SRV. However, underlying these theories was an implicit adherence to a different model of working that is called here, People First. I argue that this model is better placed to inform and guide workers about their role, because it has been developed and is continuing to develop through the experience of its members. Arguably, the People First model is more appropriate to act as guidance for support-workers because it is not being thought up and imposed by others on a group of people with very different needs and abilities.

4. Social movement

The subject of a national or social movement developed from the ideas cited above of the sharing of experiences and information (Emma, Geoff and Felix). This was apparent in the evidence of the supporters and some of the longer-standing members of the People First groups. Bersani's (1988) taxonomy of the components of a social movement (see Chapter 3) suggested that the self-advocacy movement had met the criteria.

Bersani (1998, p.265) maintains that the self-advocacy movement echoes similar phases of development in other social movements:

- writes its own history and identifies its roots
- has a manifesto and produces handbooks
- calls for equal representation of members
- demands to eliminate stereotypes
- makes good use of rhetoric and has its own anthems and slogans
- supports self-identification and raises consciousness
- seeks justice and representation
- builds alliances with sympathetic organisations but also wrestles with the role of formative segregation.

He believed that these eight criteria constituted a social movement, and moreover, that the organisation of self-advocacy groups was at this phase of development.

However, as Dowse (2001) and Walmsley (2001) contended he may be over-emphasising some points. His work was based on the American experience of self-advocacy, and this research shows a number of the eight characteristics as being problematic.

For example, in the UK, some groups have begun to write the history of the self-advocacy movement but it is not a characteristic running throughout the country and is relatively recent (see the Carlisle People First Research Group work on the History of Self-advocacy in the UK). Secondly, there are no manifestos available, of the People First philosophy. As discussed, the concept is more in the minds and consciousness of members, if it is present, rather than in any written materials.

Thirdly, calls for equal representation of members have been fraught with difficulty as evidenced by the experiences of People First National and other influential groups moving towards a national network.

The advocacy support-workers in this research were claiming that the problem with People First National was precisely that its representation was not apparent across the country. ‘Valuing People’ initiated a National Forum, and has managed to achieve equal representation across England, but its approach is criticised for taking energy away from the grassroots work of the groups (David and Moira, Group A; Ian, Group C). It was also government led, rather than led by the self-advocacy groups. This indicates a need to ascertain just how well ‘Valuing People’ has worked for grass roots groups. There has, to date, been no study on the impact of ‘Valuing People’ on the pre-existing self-advocacy movement.

A social movement does not just happen, it is a dynamic and growing process. Some individuals and groups may possess the characteristics outlined, but for a movement to grow across groups it needs to be properly networked. Della Porter and Diani’s (1999) work on social movements is instructive here. They outlined four main characteristics of a social movement (p.14-15):

- *Informal interaction networks* – where there can be a plurality of individuals, groups and organisations, that can be loose or tightly clustered, that both share information and provide a view of the aims.
- *Shared beliefs and solidarity* – a social movement requires a shared set of beliefs and a sense of belonging.
- *Collective action focussing on conflicts* – where there are high stakes desired by two or more adversaries.
- *Use of protest* – where radical and unconventional protest takes place.

In effect they considered social movements to be made up of informal networks that were based on shared beliefs and solidarity. These networks mobilised about issues of conflict through different forms of protest.

Andrew Lee, Director of People First National in addressing an audience in Italy (2003a), requested:

I call upon you all to set up self-advocacy groups in your own country to campaign against the laws that discriminate against you and start to change public opinion. When you are part of a self-advocacy group there is a power and a confidence you get from being in a group, fighting for your rights, that has a personal and political impact on your life. Joining People First was the best thing I did in my life. ...It is really important that you challenge your governments on the rights for people with learning difficulties to change your laws for the better, so the laws say what you want them to say and change public opinion in all European countries and take control of your lives.

Evidently, Andrew Lee sees in People First the making of a social movement, and so do other experienced members from this research, such as Geoff, Emma and Felix. For it to be successful and owned by people with learning difficulties, the research indicates that it necessarily needs to take time and go at a pace where people can understand the process, not at the pace of advocacy support-workers.

As Yvonne (Group A) suggested:

I don't see it as a cohesive movement but then you have to realise all movements start off as little fragmented parts doing things... the People First movement wasn't brought along with the disabled people's movement, and so they are not quite at the stage that the disabled people's movement is, where they have a national body...and a central ethos - the social model of disability is our bible. We wrote that. The People First movement doesn't have that yet.

This was precisely the point. Where and from whom will the written and shared information emerge?

There is a risk then of self-advocacy being heralded as a social movement before it is ready. The hazard is that the movement will be viewed as something without substance because it will not be seen to be shared amongst members. There is learning that has to happen in order for the movement to be owned by people with learning difficulties. The movement, if heralded before time, would then be hollow and unreal and achieve nothing other than individual empowerment. This may be good for individuals, but will be tokenistic and not achieve the political possibilities of a consciously shared (and understood) goal.

5. Management issues

The Research-team found that the group members appeared to be unaware of the potential power embedded in management practices. In fact this emerged as an area of neglect, where more time went into the everyday running of the organisation, rather than stepping back and looking at the organisation as a whole. Again this linked back to the balance of working with the individual or the group. This finding from the groups was problematic for a number of reasons, perhaps the greatest of which was the fact that of the groups researched here, the members were, in name, legally responsible for the workings of the groups as they were Directors or Trustees of their own management committees.

This meant they were responsible for the health and safety issues of the organisations, as well as the financial and employment issues. There was no

evidence in any of the groups of training on these aspects around employment and certainly members, and frequently supporters, did not seem to realise the significance of this omission. At the time of the research, Group A were training their members on management committee issues. Yvonne, the new manager, was appalled by the lack of knowledge and understanding she encountered for a group that had been running for more than twelve years. She said of past advocacy workers:

They have had some really naff ones apparently, I can't comment because I don't know, but they've had some bad buggers, and I want to make sure they don't get bad buggers again!

The lack of initiative in this area showed time and again that members who were 'in charge' of the organisations lacked access to information about the most fundamental aspects of them, including the group plan or business plan; the funding strategy; supervision; training; and monitoring of people who were employed. Even in groups such as Group C, where a joint business planning day had been held, the main contacts and decisions were made on an everyday level through the development worker rather than the members.

Andrew Lee (2003a), during his speech cited earlier, stated that:

People First is a campaigning organisation, it is different to organisations that are run by parents and carers because it is run and controlled by all the members. People without learning difficulties cannot sit on our management committee, they cannot vote at our Annual General Meetings, in short they cannot and do not decide our policies or our rules, we do.

Such rhetoric is repeated in many of the groups but the reality showed that there was a lot of work, in People First organisations, to be done on legal issues. That

is, effective training on the role of Directors and Trustees; managing staff; developing organisational plans; and applying for funding. If the control of this is frequently in the hands of advocacy support-workers alone, the research suggests there will be a gap in the knowledge of members that will impede them in genuinely managing and controlling their own organisations. There are also fundamental legal issues and responsibilities to bear in mind which are currently seriously troubling.

6. Support process

Understanding where members are in their thinking was crucial to advocacy support-workers in order to be able to give effective support. For example:

Geoff was not happy in his work at Group A, as he felt he had been given targets for his project that he could not reach.
Rohhss fieldnotes 14/01/02

In interviewing the support staff at Group A, not one of them had mentioned Geoff's worry about his targets, so these important pieces of information were not being exchanged. Geoff, far from being supported, felt stressed about his role and insecure about what he should do to change it.

The research showed that there was often a gap between what the group officially asked the advocacy support-worker to do, and the tasks they said they did. Some workers claimed they did 'a million and one tasks'. This may have the potential to build into resentment if advocacy workers feel taken for granted or not rewarded to the extent they feel they should be, as evidenced in Group C.

It became clear that there had been some acrimonious experiences where workers had left their posts or were dismissed. This was also borne out by the comments from Cathy and Collette who were on the verge of leaving their posts. Because of the lack of emphasis on training and supervision it is perhaps understandable that these problems were happening.

That support is varied and around so many different topics, suggests that the groups could benefit from more structured plans to indicate the role of the advocacy support-worker. Sometimes the groups appeared to be trying to do everything but achieving very little in a real and solid way. As Geoff (Group A) had remarked:

*If supporters knew it was a movement and a movement
for change then they would know what they needed to do.*

People First National makes a point of employing, on a full wage, people with learning difficulties and then recruiting supporters linked to each person's requirements. This means that each time a worker changes, so does the support. It embeds the idea that it is the person with learning difficulties who is the key person in the arrangement rather than organisations employing workers and then involving members. Group A was trying to follow this example.

For advocacy support-workers, this would not provide any security for their role. However, it seems that if support is to be less controlling and more geared to individuals' needs within the post, then this needs serious consideration. It also gives space to decide how much support an individual needs, and whether they need the supporter to be a person who is non-labelled, or whether they can work

with the support of another person with learning difficulties. If supporters are employed in posts for many years, continuity may be afforded, relating back to the importance of experience. However, there does seem a danger that the supporter could accumulate information and knowledge within the group, which may have a negative effect where it is not shared.

Ian (Group C) indicated the importance for each person to ‘reinvent the wheel’. By this he meant that it was important that each member went through the process of learning what the group was about and how it worked.

As the research showed, employing non-disabled people to deal with accounts, supervise staff and develop plans may well be in keeping with the ideas of empowerment within the social model of disability (where the disability organisation employs and has control of the tasks). However, it was also shown that it did little to enhance the learning and control of people who may only really come to understand such roles through an experiential rather than abstract process. The essence of this argument is that applying ideas from the disability movement directly onto people with learning difficulties is not necessarily going to work, even if the desired result is the same.

7. Power and empowerment issues

People First National have recognised the lack of control members have in their organisations and have set about trying to deal with these issues. On the topic of employing people with learning difficulties People First National outline:

We have designed leaflets to give your group on important information about making it possible to employ people with

learning difficulties in real jobs with real pay, what your group needs to do as far as the law is concerned and knowing what are the best things to do when asking people with learning difficulties what they think. You will all agree with me that it is important for self-advocacy groups to be independent and controlled by their members, not people without learning difficulties. But it is a big challenge proving to society that we can run our own organisations and it can at times be seen as very difficult.
(Andrew Lee, 2003)

The research has shown that there was a contested view of who was in control of the organisations. In the example of Group C, an advocacy support-worker felt the development worker was in control (Cathy), whereas Felix thought the group members were in control. Yet both these people have experienced the same group.

There were many issues about power and empowerment that came to the fore in Chapters 6 and 7, but perhaps an overriding point was the complexity of power issues. There were power issues within all the relationships; between advocacy support-workers; between members and advocacy support-workers; between members and members; and between the groups and outside agencies. There were a number of different levels in the struggle for power. This implied that setting the scene for empowerment needed to address all of the different levels.

The hidden aspects of power around management are important areas for development. Until these issues are addressed it will be difficult for groups to reflect on and analyse power issues in order to contest oppression within society. It may be important that there is withdrawal into a separate culture (People First) to learn how to deal with power issues and address what is going on around the lives of group members before they can effectively move out into the world and

change it (Williams, 1989). Certainly the view of the Research-team was that members should be involved in all aspects of the organisation so that they can manage things for themselves.

8. Managing change in groups

The research showed the importance of the notion that individuals and groups develop and change at different stages. It became clear that groups were never set, but were dynamic and ever changing. People came into groups at certain times but also left of their own accord. The fact that groups are fluid is an important factor in the task of the advocacy support-worker because it means that strategies for change will need to be repeated and not put into place once and for all.

The research found that relationships between workers and members could grow so there was eventually a blurring of distinctions and the group was made up of 'people' with a common aim. If this is the case then the question arises as to how that fits with advocacy support-workers having job descriptions and being paid where group members are not. This is the point for Wilson's (1997) conception of 'partnership' working within self-advocacy groups.

Other facets of managing change in groups included the tendency for larger successful groups to start developing smaller satellite groups (Groups B, C, and D). The experience Group C had was that the smaller groups took members from the original groups with them, which weakened the infrastructure of the original group. This left them feeling at a loss, while the smaller groups grew and

flourished. Perhaps it is useful to consider how this development can happen and still allow the original group to maintain its own strength.

Another issue was how to help members manage their disappointment when they had been powerful officers but were not re-elected, (Groups A, B, C and D). It was clearly difficult to help people move on and create space for new people at the same time. It could be suggested that perhaps there were tasks that members could take over from workers as they learnt more about how their groups worked. There may well have been bridges and links to be made into the mainstream world of work for people who had gained expertise.

Managing change was a real dilemma in self-advocacy groups, yet one that received little attention as far as the research could ascertain. If these changes and their impacts were understood and discussed, the groups might harness the strength, knowledge and expertise of people ready to move on, to help the group's survival.

9. Conclusion - what light does this shed on the purpose of self-advocacy groups?

Key issues emerged through the research that, if resolved, could help strengthen the position of groups and make clear the role of the advocacy support-worker and, therefore, the purpose of the groups and vice-versa.

Reviewing the perspective of advocacy support-workers in relation to that of members suggested that where there were differences in views, effective

communication was required to fill the gaps. Groups needed to know where the differences of opinion lay. The research revealed the following key issues to be addressed:

Clarity about what the group is set up to do.

If the group worked out a plan that was coherent and shared by the members, then each person's tasks could be outlined, monitored and managed. The problem shown by the research is the myriad of conflicting demands placed upon the role of the advocacy support-worker, suggesting an almost impossible task. Members' ideas of the role ranged between wanting protection, to supporters staying in a background role. This suggests that everyone involved needs to step back and reflect on what it is that is wanted from the role in each group and then try and develop plans around it.

An awareness of the hidden issues of power in the management and structure of the groups.

Advocacy support-workers currently have more power than is constructive for the members of the group. If the members were supported to understand more about the structure of the group and the management issues, they would be able to fulfil their legal duties and be in a position to manage their workers. This can only be done through making all facets of the organisation accessible in every way and enabling people to learn through experience.

Training and development of members into the worker's role

There appeared to be no reason why people with learning difficulties were not employed as workers for their own organisations. That is not to say supporters are no longer required, but it may be possible that the dynamic of the relationship would change if workers with learning difficulties were also on a salary. This would provide a positive role model for new members, as observed in the actions and perspectives of Geoff, Felix and Emma.

Groups needing to communicate more over problems

‘Time’ has constantly appeared as a problematic point of tension within the organisations, and a reason for things not being dealt with in a proper ‘People First’ way. Supporters were acutely aware of this happening. If problems within the group were discussed and solutions found, then it set a precedent for dealing with problematic issues outside the groups around power and oppression. If issues over accessibility were addressed, there appears to be no reason why members could not easily be kept informed about what is happening within their groups, as they are officially ‘in charge’ of the organisations.

Importance of ownership of documentation

The findings in Chapters 6 and 7, highlighted the gaps between the official rhetoric found in documentation, including job descriptions, and other written material about the advocacy groups and the support role. This was in contrast to the actual ‘lived’ experience of the members and advocacy workers. What was interesting was the generation of the official documentation; often material that had been brought into groups or passed over from other voluntary agencies or

statutory services. It is possible that the documentation was brought in to help with ideas for creating 'People First' official papers. However, it was clear that much had been copied and re-used and therefore 'applied' to the organisations from the outside, by advocacy support-workers. This was definitely the case for Groups A, B and D.

Self-advocacy support as a unique role

The culture of service agencies and other voluntary groups was so markedly different to what was happening in People First, and in the make-up of the individuals running the groups, that the process of exchange may not, after all, be helpful. The review of literature pointed to the isolation of the advocacy support-workers in terms of other roles within services for people with learning difficulties, such as a personal assistant or day care support-worker (see Chapter 3).

It may be that acknowledging the unique characteristics of the role is a strength rather than a weakness. It could act as a reminder that no one is really in a position to say what the role of the advocacy support-worker is until people have discussed it in their own groups. As Wilson (1997) pointed out, perhaps the role of advocacy support-worker is a 'particular type' of development role.

Viewing the People First group as a whole

It seemed important that the groups were clear about their own ways of working and the processes that worked best for them. Opportunities were needed to apply these processes to the entire workings of groups, so the parts of the organisations

could hang together as a coherent whole. Currently the organisations appeared ‘incoherent’ in this way because the ‘People First’ model of working was not equally apparent across all facets of the organisations.

Any People First organisation using other groups’ guidance is setting up intrinsic barriers, indeed the type of barriers that the group may well be complaining about in regard to outside organisations. This point seemed to have been missed by most of the supporters in the study apart from only one (Ian, Group C), who stressed the importance of ‘re -inventing the wheel’. A group learning what it is legally responsible for, and setting its own (accessible) guidance and policy appears to be of crucial importance if Directors are going to be genuinely responsible for their organisations. This area of neglect is potentially legally disastrous for groups if it continues unaddressed.

The People First model helped gain an understanding of the particular requirements and idiosyncrasies of self-advocacy organisations. It appeared that the role of the advocacy support-worker, if dictated by the different needs and characteristics of members, would be slightly different in each group. Therefore each group would need to develop the boundaries of the role for themselves. However surrounding that very detailed work could be some of the main points raised through this research that seem to constitute what, on an ideal basis, a People First group would look like. The research has also helped to define the areas of risk and pitfalls.

Advocacy support-worker roles vary depending on what, if any, model of support the group adopts; a social, People First, or partnership model. What the research has shown is that there are key areas to be addressed within the groups in order to establish a shared vision of where the movement (and therefore the support-worker role) is heading.

Not only does the theoretical underpinning affect the role within a group, but the support-worker takes on multiple roles within their task. They move in and out of different roles, with different people, and during different activities, some requiring more support than others. The point is that workers need to be consciously aware of these shifts in order to understand the power dynamics happening within each interaction and change.

The knowledge gained from the perspectives of the advocacy support-workers and the members, about what the role entailed, suggested some clear areas of training needs. The training suggested links back into the views of what the role should be, also based on the stated People First ‘way of doing things’. Training for support-workers, grounded in the support-worker and members’ perspectives could help workers to be aware of the background theory they draw upon and avoid conflict amongst themselves (Group A; Group C). This training could focus on:

- The history and experience of members
- The individual access and support needs of members
- How to make information accessible
- Effective communication

- Facilitation skills
- The importance of process, action and experience
- The stages of development of a group and of a social movement
- Legal rights and responsibilities.
- Awareness of role and role boundaries
- The importance of reflexivity.

These aspects of training would help to tie together the competing elements of individual versus group requirements, by ensuring that individual support needs were met to enable people to understand and make links with the wider issues.

This training would, of course, need to be supported by effective monitoring and supervision.

The last two points on the list of training needs highlight the importance of reflexivity. Support-workers could be encouraged to clearly analyse the different roles they occupy and different times to appreciate the dynamics of power happening in specific situations. This will require supervision. If this were to happen the multiple (and therefore confusing) roles of the advocacy support-worker could be broken down and analysed. They could then check that they were ‘not taking over’, but only providing the necessary input an individual required.

This can be illustrated overleaf:

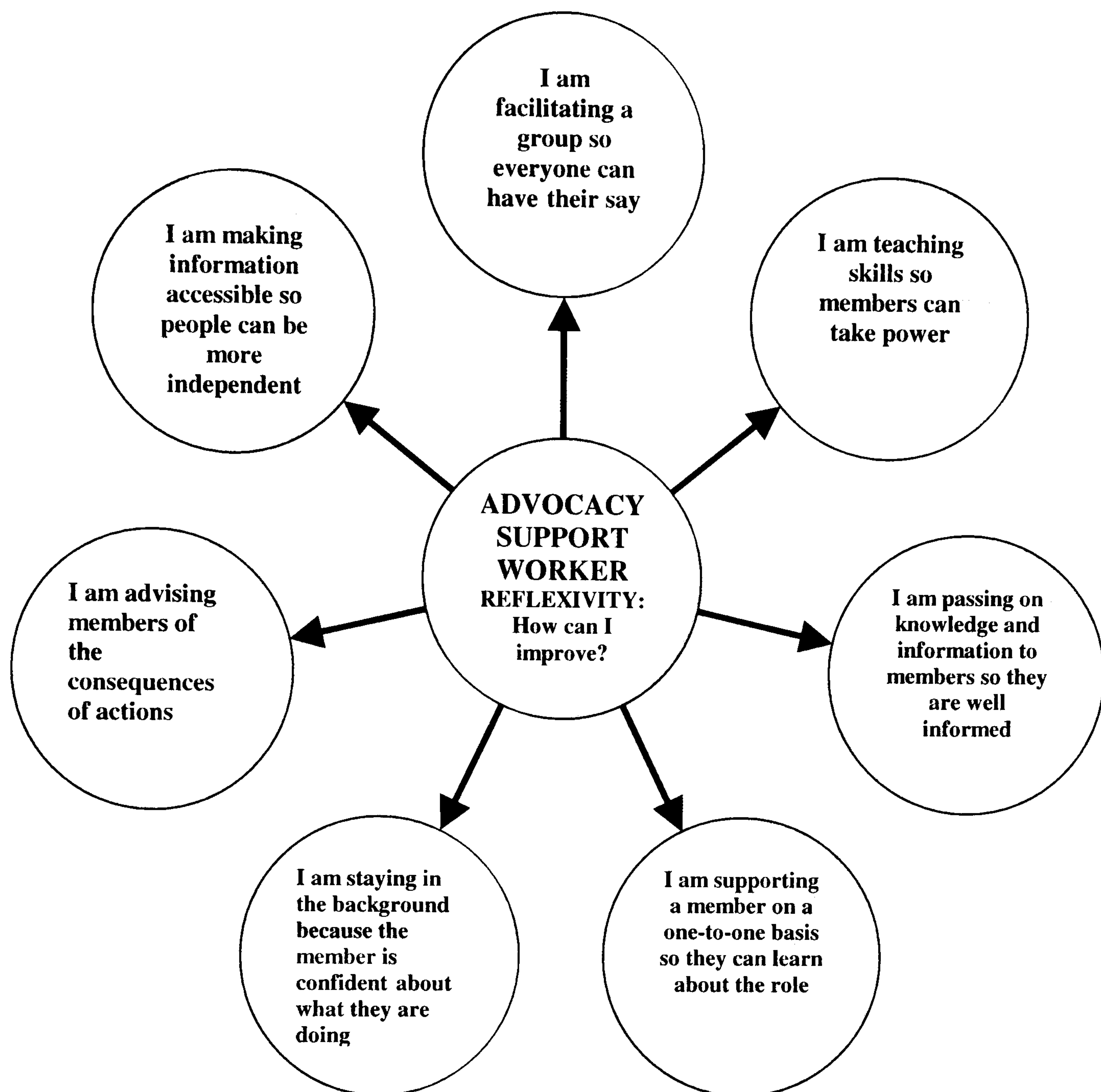


Fig. 4: Reflexivity over the different roles within advocacy support work

This chapter has discussed and analysed the commonalities and differences between support-workers and members' views as to what constitutes the advocacy support role. It has been suggested that a People First model of understanding the groups could help supporters to realise and harness the important aspects of empowerment for members around the key concepts of process and experience. These concepts would be individualised within each group, possibly conflicting with achieving the more global conditions of a coherent social movement.

The next chapter outlines the development of the Research-team during the process of this project. The last chapter returns to the main findings of the research and discusses some of the implications.

CHAPTER 9

REFLECTIONS ON WORKING AS AN INCLUSIVE RESEARCH-TEAM

This chapter reports on methodological findings. It links back to Chapter 5 and seeks to reflect on the process and merits of working together as a Research-team.

The chapter begins with an explanation and rationale for using a team approach. Moving from this to the actual project itself, continuous reflection of the methodological approach was viewed as crucial because inclusive research is a developing area. It was therefore essential to analyse the process the team experienced throughout the course of the project. The following report lays bare the inclusive research process as an attempt to provide ideas for other researchers to build on and develop in the future. I felt there were three major areas of significance to the ongoing development of the group process so I have organised the discussion under three main headings:

- Learning about Research
- Roles and Relationships
- Practical lessons.

These reflections are discussed with ongoing summaries as to what was found to be important, useful, or a barrier to inclusive research. The future of inclusive research and of the Research-team is discussed in Chapter 10.

Rationale for Team Research

The rationale for conducting this project through an inclusive Research-team approach was focused on four main influences. Firstly, as indicated in Chapters 1 and 2, the current policy on self-advocacy seeks to promote the inclusion and participation of people in all aspects of their lives (see *Valuing People*, 2001; *The Same As You*, 2000; *Fulfilling the Promises*, 2003). Therefore, in the current policy climate, this is a timely project, especially as the subject was about self-advocacy.

Secondly, in the academic arena, inclusive research was a developing but fairly uncharted area. As explained in Chapter 4, there are debates around the ability and potential of people with learning difficulties to be fully engaged in the research cycle (see Clement, 2002; Minkes et al, 1995; Stalker, 1998; Tsuda and Smith, 2004; Ward and Trigler, 2001). Given that we had already worked together on small pieces of research, we were well placed to add our voices to that debate.

Thirdly, the organisation Carlisle People First, had an established Research Group²⁷ prior to this project, which I had supported as part of my previous job.

They had managed to undertake some research and consultation work.

Additionally Andy, Malc and Lou were involved in tracing their life histories, but there had been little opportunity to develop a larger project within the group. My studentship at the Open University afforded that opportunity.

²⁷ The title of the Research-team has changed through time reflecting different stages of development. This is written about by Chapman and McNulty, 2004. It is also discussed later in this chapter.

Fourthly, it was methodologically appropriate, given one of the research questions required that the perspectives of members on the role of advocacy support was sought.

The strength of the team approach, as described in Chapter 5, was that it engaged two insider perspectives in relation to the research topic:

- Self-advocacy support-workers
- Members of People First groups.

Although there were tensions and issues of partisanship to address, (Chappell, 2000; Hammersley, 2000; see Chapter 4), I contend that the team were uniquely positioned for this particular piece of research. As part of my studentship, I could have undertaken the project as a lone researcher. However, that would have left this research without the views of members, thus going against the ethical principles brought to our notice by other People First groups (see also Aspis, 2000).

However, as I already explained in Chapter 5, the pilot study had confirmed that members of People First groups were more relaxed talking with peers. It also appeared that members were more sensitive to power issues inside a group.

Likewise, I felt support-workers were more likely to be honest and open with someone who knew about advocacy support issues, rather than an ‘outsider’, or a person with learning difficulties as a researcher, whom they may not want to ‘upset’.

This is not to say the process was completely right or to deny problems within the process. The next part of the chapter will look at these problematic areas in more detail.

Learning about research

Although the team had established relationships when we entered into this project, we had never attempted a long-term project before. I had worked with the group since 1990 and the Research Group was set up in early 1999 to focus on learning about research.

My role at this time was as a supporter and facilitator to the group but I gradually became more involved in teaching. Niall joined the group as a support-worker when it was already established, and, as he explained himself, did his learning from the group (Chapman and McNulty, 2004).

Learning skills of research within the project

When the Research Group began this project, the learning continued. As each stage of the project was reached and worked on, it became a journey of discovery with a number of unexpected twists and turns.

Topics raised at weekly meetings reflected events that were happening in people's lives at the time. These events would be discussed and, if possible, incorporated into learning about research. For example, the early discussions on support-workers focussed on incidents that had happened in the Carlisle office or at

conferences with people over the years, and especially where there had been highlights or problems. The notes from one of the meetings reflected this:

*Lou remembered there had been a 'bad' support-worker
at Swanwick [conference], who had bossed everyone around.*

and:

*Andy remembered his first conference at Castle Priory.
He said on the first night there had been a big conference...
'I was the first one to speak up and ever since that night
that is what I have done'...(RG meeting notes: 2nd February 2001)*

Although people's experiences informed the discussions and subsequently the planning of the project, I found myself stressing the importance of standing back and keeping an open mind. In this way I saw my role as counteracting the very personal approach the team members took, and tried to balance the discussions with a more classic research approach. This was partly my concern about what was viewed as 'research' by others, and partly because I wanted to encourage a reflective standpoint.

False starts

There were a number of false starts with the project. We initially intended to send questionnaires to all the groups in the UK, following Goodley's (1998) example. We spent weeks designing and repeatedly rewording an accessible and illustrated questionnaire, then tried to find the funds to send it out.

We came unstuck as we attempted to access a database of addresses, as no-one passed over their information to us, due to data protection. Moreover, I could not simply walk into the Carlisle People First office and use their address file.

Another group did send out an information sheet on our behalf using their own

database. When groups replied, this supplied us with 43 addresses of groups to invite to a History-Workshop.²⁸ Although we had not been able to send the questionnaires, we did have invaluable information for the history work.

During the team discussions, as we reviewed the situation, we agreed that questionnaires had not been the right method for us to use in any case, because they involved dependency on other people. That is, people would need support to fill them in. The team decided that talking to people, person to person, was a far better option than questionnaires. They also agreed that not building dependency was an important issue, and something that should be avoided. However the team had learned how to design questionnaires!

Another major change came when the group decided that they would take ownership of the history aspect of this research project, because it was about their movement (see Chapter 5). We had previously devised together an illustrated ‘River of History’, a kind of timeline, where all the important events and issues the team could think of pertaining to self-advocacy development in the UK, were drawn as tributaries. The river became more complex with illustrations of rapids and rocks, where problems had occurred. This work filled a number of sessions and was exciting, as everyone was involved in the idea. The team wanted to add other groups’ views to the River. I had initially intended to research the history of People First groups as background context for this project. However, this change in ownership restricted my focus to the history of the support-worker role (see Chapter 2).

²⁸ The team used these addresses to invite self-advocacy groups to the History-Workshop in

Because of our discussions around ownership, and who should be able to research issues to do with members (see Chapter 5), it was decided that if I helped the group with their History Project, they would help me with my research on supporters. In essence we ‘struck a deal’ and split this project into support-worker and member perspectives.

The History-Workshop involved a lot of hard work in organising and practising for the event. The workshop was held by the members of the team in Birmingham, in July 2002, funded by a grant from the Open University, as it was connected to my project. I later transcribed the tapes and helped write an accessible report (Carlisle People First Research Group: The History-Workshop Report, 2002). The tapes were full of insights about process, as well as the content of the workshop around history. However none of that material was used in this project because it belonged with the team to do what they wanted to do with it.

To have the opportunity to learn research skills is essential (Walmsley and Johnson, 2003; Williams, 2000b), if people are to be in a position to become involved as credible researchers. The negotiations and agreements we made within the Research-team reflected the pressing need to give something back, especially where finances were not available, rather than just take from others or, as Aspis (2002) accused, take advantage of people for academic researchers’ own ends.

The experience of undertaking this project has shown that learning happened at all stages of the research process, and it was often multi-faceted in that everyone was

Birmingham (2002), after we had decided to separate the project into the two different parts of

learning. The group may have been learning about traditional research skills, but equally I was in the process of learning how, for example, to be more sensitive as an interviewer (like Andy), or how to make the process more accessible and consider a wider perspective of individual needs. These were important issues to reflect upon because there are inevitable omissions. This project did not, for example, venture into attempting inclusion with people with profound, multiple and complex needs as researchers (see Caldwell, 1996; Gluck and Patai, 1991). Firstly, they were not the people I had an established relationship with who made up the Research-team. Secondly, there is also a point about informed choice. All of the people involved in this project were already motivated and committed to the idea of being or becoming a researcher. Including people with profound and complex needs as researchers would require careful study in itself, unravelling issues of self-election, and possibly focussing on the use of specialised recording equipment and communication tools. However it may well be very important to establish some precedents at the level of inclusion of this project, to form a foundation to build upon.

The team explained in their article (Carlisle People First Research-team, 2004), that their research is always about two things: a) the actual research study they are undertaking; and b) telling other people about research.

This emerged as important to the Research-team because of their awareness that other people with learning difficulties had limited knowledge of research, or indeed of issues a research study may focus upon. Chapter 5 detailed how Andy

and Elizabeth were insistent that it was their place to tell people about ideas to do with their own movement, if they did not already have the knowledge. Therefore the research was also a teaching and learning experience for the participants.

The view that participants in the research are learning as well, links back to the importance placed on:

- Reciprocity in the research relationship (Oakley, 1981; Mies, 1983; Shakespeare et al, 1993).
- Action research (Dash, 1999; Elliot, 1991)
- Ensuring research is empowering and of use to the people it involves (Oliver, 1996).
-

The point is that the research became a dynamic process, beneficial to all.

In learning about research, a record of a session (July 2000), just prior to the project starting, illustrated how these questions of benefit and usefulness were perhaps more important at the outset than the actual research itself.

Fig. 5, as shown overleaf, is a copy of flipchart paper from the research meeting. However later, as the ideas developed, (February 2001), there was a difference that could be tracked. By this point the Group had learned about the whole cycle of research and had become aware of the value of looking at ‘what had been researched previously’, as well as fully discussing ‘the most appropriate methodology’:

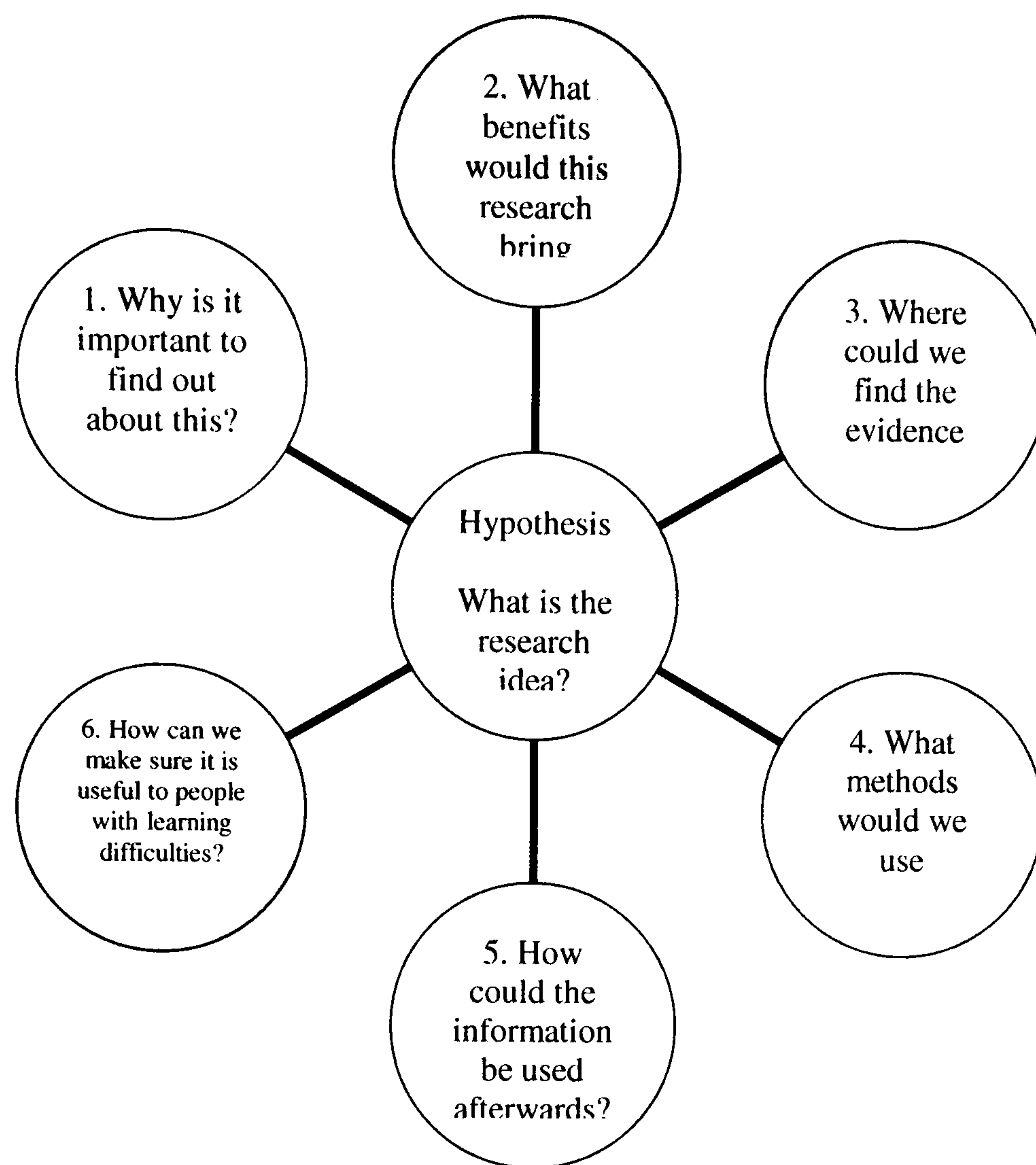


Fig.5: Summary of Team discussion on the Research Process, July 2000.

When we looked at other people's research, I read out articles and explained the work of people in as accessible language as possible. Occasionally Lou (being the only other reader) would borrow books, and then return to the group with a précis of what she had read. We also watched videos of relevant topics, for example, 'Stolen Lives', to enable more discussion around experiences of institutional life for Andy's own piece of research.

Learning about other people's research is difficult for researchers with learning difficulties because it relies on written language, and not everyone has had the chance to, or was able to learn to read and write. The team found the writings of

Simone Aspis (1997; 2000), plus the books '*Good Times Bad Times*' (Atkinson, McCarthy et al, 2000) and '*Know Me As I am*' (Atkinson and Williams, 1990) particularly useful. The latter two books included accessible illustrations. At this point a research supporter has a crucial role to link people into what has happened before, including any written material.

Summary points:

Two main points emerged from reflecting on learning research skills throughout this project. Firstly, that learning about research in this project was dynamic and had no boundaries. Secondly, issues of accessibility were constantly guiding the way the group worked.

Framing the project

The methodological literature in Chapter 4 pointed to the fact that most inclusive research involved people with learning difficulties after the main ideas for the project had been formulated by the lead (non-disabled) researcher (Mitchell, 1998; Minkes et al, 1995; Townsley, 1995; Tsuda and Smith, 2004). The team was not very impressed by this view and was keen to challenge it.

The literature suggested that in many instances lead researchers had not worked with the team they were involving themselves with until later in the project development. Certainly Mitchell (1998), like Clement, (2004), did not approach co-researchers until they were sure of their study area. Mitchell was, in addition, looking for people with specific characteristics:

I wanted people who had lived with their families or recently moved out...I considered it was also important to find people who were fairly capable...four people came forward as possible co-researchers. (p.126-7)

This research project on advocacy support-workers was different, because we had all previously worked together. There were no issues to work through around 'specific characteristics', because our working relationships were developed beyond that stage.

When we had initially met, I was in a support and development role at People First. There had been no issue around a person's 'characteristics' or 'capabilities' as the people involved were my employers. I think this may imply that the characteristics and capabilities of the person are perhaps not particularly important, more the familiarity within the relationship in order to know how to support a person's individual access needs.

In the Research-team, we negotiated our roles across different projects. We were all involved in doing something we had generated from our own individual ideas, other than Niall, who was employed purely as 'support' to the members of the team.

The initial idea for this project, to research around the role of advocacy support-workers was mine. From that point onward discussions took place within the team over how that would become a project, involving other peoples interests and developing an inclusive approach. This led to a meeting at the Open University in March 2001, between my supervisors and the Research-team. The purpose of this

meeting was to establish that we all had input into the project, but also to give the Research-team an experiential view of the University and meet up with academic researchers. This had the added bonus of moving discussions about the university from the abstract into reality.

One member of the team had very strong ideas about what research should be seeking to do:

We need to do the research, for people with learning difficulties to say what needs to be done. Professionals need to look at how they've destroyed people and what they are going to do about it. (Malc) (RG Meeting notes: 11th July 2000)

Summary point:

It is possible for people with learning difficulties to work as researchers and frame the ideas of their own research projects. The History Project demonstrated this and the Research-team continues to work in this way. The barriers to people undertaking their own ideas in research are more to do with the power wielded by academic bureaucracies and funding bodies (Goodley and Moore, 2000). It is important to separate the issue of the power of the academy from the 'capabilities' or 'characteristics' of people as researchers.

Preparing for Fieldwork

When all the fieldwork sites were negotiated and planned for the project, we set about the task of fieldwork together. This was only possible because I had access to extra funding from the Open University for the Research-team's travel and accommodation. These funding considerations are important. The lack of even a

small amount of money (relative to the overall costs of research) can be a major barrier.

The visit to Group B by the Research-team involved working through a number of access issues. Firstly we had to hire a minibus that was adapted to take people using wheelchairs, and a considerable amount of equipment. We also had to book accessible accommodation that was not too far from the site, and where we could easily get meals. Andy and Niall and Lou and I shared bedrooms to keep costs down.

The pre-fieldwork meeting mentioned in Chapter 5, (see Appendix 8), gave insight into the emerging roles of the team members as individual researchers.

During the meeting, a number of points about inclusive research emerged. By this time, Lou had taken on a role of researcher-as-expert-through-experience.

Because she had been involved in fieldwork with Group C, she had already been through the process of fieldwork for the project and willingly passed on the things she had learned to others. This highlighted the porous boundaries of the group members and the didactic nature of the work.

Moreover, Andy's question about whether we should judge others or not positioned us centrally in the debate around the researcher as objective or as partisan. He and the group were aware that they had comparisons to make from their own experiences and, in discussing it, there had been awareness of the complexity of distancing oneself. To be reminded of this dilemma the night

before fieldwork commenced, was timely and it was something we came back to many times in our discussions. It also brought about the realisation that although concepts such as ‘objectivity’ had been fully addressed within Research-team meetings, actually participating in research made the dilemmas real and part of people’s experience, and therefore easier to understand.

Summary points:

A number of points came to the fore during the pre-fieldwork phase. Firstly, funding is essential if people are going to be able to participate in inclusive research. Secondly, people’s roles change and develop as the process gets underway. Thirdly, the actual doing of research makes the project come alive and creates a more supportive environment for meaningful discussion to take place.

After the fieldwork

On the first evening, before our meal, Lou sat at the dressing table in the hotel room, with the laptop set onto large print, typing her fieldnotes directly. After I had written my own notes, Niall took dictation from Andy and I took dictation from Malc.

When I read over Lou’s notes I felt they were a little scant and asked further questions to illuminate some of her points. I recorded these in italics to be aware of the additions. I explained this to Niall and he used the same process with Andy. I also asked Malc to add some points during his dictation.

The purpose of this was to move the description further, to enable a richer view of what had happened. I then transferred all of these notes to the laptop so that we completed the recording process before the next day. The process was exhausting but after our meal we could talk about the day's events and then plan again for the following day. This process was followed each day.

Summary points:

There are two points here about research support. Firstly, support takes a lot of energy, as it is time consuming. I needed to 'think on my feet' as team leader as issues became apparent, such as prompting for further information but also making sure it was recorded in a different way. Before we arrived we were all unaware of quite how long the post-fieldwork process would take. Secondly, support needs to be flexible, change and adapt as people take on new and different roles, allowing the space for people to develop. Again, we did not know before we arrived that Lou would type her own notes. It was important for Lou that she took on the tasks she felt able to do thus encouraging her participation and involvement and, at the same time, lessening her dependency.

Roles and Relationships

There are a number of issues to discuss around the roles and relationships of the team members. It is important to draw out differences, in order to clarify roles and enable further work to build upon the findings of this methodological process.

Individual approaches

Each member of the team brought their own individual approach to the research process, despite the fact that all had been through the same learning process within the Research-team in Carlisle. This, of course, is true for any researcher who has a

history of experience behind them, and a set of interests that they have individually developed.

Reflecting on aspects of becoming a researcher had led the group to define their concept of 'person-led' research in their recent article (Carlisle People First Research Team, 2004). This process indicated that each person had different ideas, experiences and access needs.

The Research-team, like the self-advocacy groups, was also fluid. Although Andy, Lou and Malc were involved in fieldwork not everyone went to each of the sites, due to illness or other arrangements. Lou managed to go to each site, barring Group A. Andy went to Groups B, D and E and Malc went to Groups B and E.

At the beginning of the process there had been another member of the team, Fred Spedding. He left the group soon after the project began. We also gained new members along the way, John Dias and Susan Macauley. They had some limited involvement at the stage of data analysis. Elizabeth Harkness was present throughout the planning and analysis, and although she was involved in articles and presentations, she had been unable to participate in the fieldwork. Niall supported the team in planning, in fieldwork (Group B), and during the analysis stage. I have analysed my understanding of each of the team members in the research role, to determine how that affected the work as a team.

Rohhss as researcher

I described at the outset that my role as researcher and team leader had been integral to the whole research cycle of this project. Although we worked together as an inclusive Research-team, I felt justified in claiming ownership of this particular project. The tensions around ownership were a constant struggle during the first year. However, as we negotiated our own pieces of work and I discussed my concerns with my supervisors, I had felt more relaxed that we could proceed without my feeling I had simply exploited my colleagues (Aspis, 2002). It took me some time to step out of my 'supporter' role into the 'researcher' role, and realise what the differences were (see Chapter 5). At the beginning of the project I was convinced they were almost the same thing.

Although I have endeavoured to keep information running back and forth and dialogue open with the team, I have inevitably spent long hours working on my own. Initially this was around the reading and literature review, and of course in later stages the writing became a necessary part of the thesis. At the reading stage there emerged an additional role for me to take on; that of teacher. The things I had learnt, as background for the thesis, had to be taught to the team so we would all be working from a similar level of understanding. Teaching was not support, as it was not a background role, it was about passing over information I knew. If the team were interested in the support role, they needed to learn from it. This teaching inevitably raised discussion and added further considerations for team planning.

The pilot study in Group A was the only part of the project where I acted alone as a researcher. Although I felt the data gathered there was adequate, and that I had been able to work effectively alone, I was convinced that the findings would have been richer with the involvement of the team. Working as a team in any case allowed more information from different perspectives to be gathered, which ultimately enhanced validity. Working as an inclusive team afforded the unique ‘insider’ perspectives that I contend have been the strength of this research.

I was not comfortable to continue as a lone researcher after the experience in Group A, because I felt I was encroaching on other people’s ground. Because of this I recognised that I had been challenged by, and had reacted to the ethical demands coming from other People First groups and other individuals (for example Bright, 2000; Lee, 2003b; and Aspis, 2002).

My role as researcher in this study involved me as a researcher, a teacher, a team leader and a supporter. I was the person in the team who had expert research knowledge to pass to others, or at least I was able to act as a bridge, to inform others where they could go to find things out. I also asked the team to reflect on my role as researcher during my absence, to ascertain whether we had a similar viewpoint. This is what was reported:

Rohhss is good at research and knows what she is talking about (Malc).

On my first field trip I felt I learned a lot - my only drawback was members would ask Rohhss when it was my interview instead of asking me. But Rohhss would respond by saying to the person, ‘Ask Lou’.

There was a lot going on and Rohhss had to take many roles from support worker and researcher and teacher. She adapted.

The only criticism is that she was worrying about what was happening like on the visit to Group E. Malc was ill, so that caused stress.

I did some of the transcriptions and most were easy but sometimes there were long words as Rohhss was asking the questions. But it was more like a conversation than a question and answer session.

Meeting Notes by Lou: 21/02/04.

It was clear that the team trusted me as a researcher to guide them, but that issues for the team revolved around their status as researchers and access issues. It was also interesting that they were affected by my reactions to stress when Malc was ill, which may have been difficult for them.

Summary points:

The things I have learned as a researcher from the team, have been about the need not to rush, to take time for ideas to be properly digested and then discussed. It is important to be very organised and completely on top of the recording process when working with a number of people. I have also learned from Andy about giving a lot of space and acting sensitively during interviews with members. Because of my experiences, I simply did not understand the depth of issues around accessibility, inclusion and power that came to the fore for the rest of the team. However, my strength was that I brought knowledge and information to the team, and could teach research skills. I also learnt the difference between co-research and support.

Malc as researcher

The further details prompted by Niall and myself in the recording of the fieldnotes probed each person's view of what had happened and encouraged them to think deeper about it. As it had been the first experience of fieldwork for Malc and

Andy I think they were unused to detailing what they had seen in depth. Without the probing, the notes would have been very basic.

Neither Malc nor Andy wrote, but a similar process of recording happened whether on tape or through someone taking dictation. To keep the notes accessible and available to Malc and Andy it was important to do them on tape.

By the end of the fieldwork, and into the analysis phase, the team relied much more on audio recording. I realised that typing up transcriptions was really only important for me, rather than the whole of the team, as most of the interviews were taped. When I realised this, I stopped delaying the analysis to wait for the transcriptions.

An example from Malc's notes is shown below. The insertions in bold are what Malc said after Niall was probing:

*I felt that today was very good. Meeting all the people and looking around the offices. They were all very good except for one (Donna's next to Gerald's). **There was smoking in there and the walls were dirty.***

*Talking to Gerald was very good because I was giving him ideas and talking about bullying and he gave me the address of someone to contact about bullying. **Gerald was smiling and nice to talk to.***

Note the repetition of 'very good' and how Malc gave the respondent ideas rather than just finding out the respondent's ideas. However this proved useful for Malc

as he got a new contact for his anti-bullying campaign. Again there was a reciprocal dynamic.

Next I had a look around upstairs at the offices. I thought two of the offices were very good. I took some photos, then we all had lunch.

I then did an interview with Sam. I thought it was very good. We have different accents and sometimes it was hard to hear what he was saying. He was dressed very well and gave good eye contact. He said all the things he had to say and that I asked him. I could hear some of what he was saying but some I missed because he was talking low. I thought he was nervous and shaky in the interview. Interviews can be hard.

We had spent time in ‘learning about interviewing skills’ which included going over the importance of noticing body language. This had obviously made an impact on Malc as he had remembered it from the session. At this point Niall probed further to add more details to his notes:

Niall:-You asked a great question about what he would do if he was a support-worker and saw someone who needed help?

Niall used praise of Malc’s actions to encourage further details:

Malc: He said he would go and ask them what they wanted him to do. He was not a support-worker though, and if he wanted to be he could get training.

Malc saw no barrier against a person with a learning difficulty becoming an advocacy support-worker.

Niall: What do you think he was feeling when you asked him that and about what a support-worker’s job is?

Malc: *I think he was feeling totally lost and shy about it. I said I would send him a copy of the report and send it to him even though he was leaving or I would send it to the manager.*

Niall: *Who is the manager again?*

Niall was asking to ascertain if Malc had picked up on the power structure in the organisation. Gerald was a member of support staff:

Malc: *The manager is Gerald*

Niall: *Who do you think runs the office and the group?*

Malc: *People with learning difficulties, they are the bosses.*

Niall: *Who answers the phones in the offices?*

Malc: *Ruth...and I think that is wrong. It should be a person with learning difficulties.*

Niall: *What do you think about the last few days in the [Group B] office?*

Malc: *It's a marvellous job they are doing. Putting the files together, meetings and working together. We do things like that but not in the way they do it. It was hard sometimes to hear what people were saying. Some were very good speakers, Margaret and Martha. They said some things perfectly and some things they didn't. The one with the t-shirt didn't say much at all, in fact I don't think he said anything. He maybe was shy, he was amongst people he didn't know.*

Malc's fieldnotes 22nd May 2002

On the previous day I asked Malc to reflect on his role as researcher:

I thought long and hard about being a researcher today I thought it was very good. I think it's hard because you have to find out people's storylines and what they are. I feel like I've worked

hard today.

Malc showed great empathy towards people who were shy or uncomfortable as the subjects of research. Yet Malc's approach to research was very much as an action researcher. He was inclined towards an exchange of ideas and taking on a teaching role rather than simply gathering ideas from others. Malc's main role at work in Carlisle was as a campaigner and seemingly he had taken this role with him into the field:

Malc sees lots of issues about everything. He came over as very rights-based. He was interested all day in what was happening. There was talk by the team about the inaccessible staircase. Malc was emphatic in front of others that everywhere should be accessible (despite this not being the case in his own office in Carlisle, he neglected to mention this point.) Rohhss fieldnotes 21st May 2002

The following day I recorded my observations of a group meeting facilitated by the team:

Niall made two interventions at specific requests but otherwise it was steered by Lou and then it became a flowing group discussion sparking off comments reaching into new ground (see separate notes and tape). The questions about support didn't really get answered here, but lots of other things did. Andy and Malc became questioners and then speakers, Malc was very strong in his views about how People First should be. It was a real exchange. When this ran out of steam we had coffee. The team and Niall went to look around the office and the files of the courses and I worked with the members for an hour on their views of good and bad support using life size body maps. The team were not present here. This was planned purposefully as I felt Malc's ideas would be very strong and might influence the group member's ideas.

Rohhss fieldnotes 22nd May 2002

Clearly as team leader I had engineered space to enable research alone at this point.

There were other specific points that Malc did not question, like his assumption that Gerald (a support-worker) was the manager, even though Malc had spoken about how members should be in control of their own organisations. These aspects were discussed later by the team during analysis, but it was interesting during the fieldwork to notice different layers of interactions between the researchers and the members and staff, and what was thought relevant and what was dismissed.

Summary point:

It was clear that Malc used some of the skills he had learned in the research group around interviews and use of body language. He was extremely empathetic towards people, particularly those who were quiet and shy, and was very respectful of our hosts. He was involved in drawing comparisons between the group being researched and his own group. He used the opportunity to learn more about how different organisations run in comparison to his own. Malc was also keen to inform people about his anti-bullying campaign and how he thought things should be in People First. This shifted him away from researcher and into the roles of teacher and campaigner. It may be that it was difficult to establish an independent perspective on the data.

Andy as researcher

Andy's approach to research was different again to that of Malc, and indeed all of us. In his fieldnotes he appreciated the welcome and hospitality shown by the group, but clearly used his own experience as a point of comparison, as

highlighted below. This was significant because in my approach to research I had tried to use a theoretical model of what support in the groups may be based upon.

It was very instructive and the people who were there, they were very helpful. They showed us what they do. The interview with Ruth was very good, she wasn't shy, it was her choice, which is right. Also we knew more about them because they told us.

Andy's point that the interview was instructive was slightly different to Malc's views that the group could learn from us.

It annoyed me that the phone went off and we had to stop the interview. That's why I asked her if she wanted the interview in that room or not.

The only thing that gave me problems was the stairs. I would have liked to have gone upstairs.

The hospitality was good because they gave me cups of tea.

Again Niall tried to expand on the information with probing questions:

Niall: *What was the interview like?*

Andy: *I felt that she had very good eye contact and looked mostly at me*

Niall: *Could you say more about the Group B office?*

Andy: *People who go upstairs would be knackered. For me to work there it would have to be different, more organised.*

Again this illustrated that Andy imagined what working there would be like for himself, within his own experience.

Andy: *Ruth does the letters and typing and phones- not the wages though- but she should be taught.*

Niall: *What things would you change in the office?*

Andy: *More space, more access. The files should have been locked away in a cabinet. I like the Carlisle office there's more space and more computers. I only saw one computer. There wasn't many meetings. How can you be a People First group without any decision meetings?*

Niall: *What are your feelings on the office?*

Andy: *It was a nice office but it could have been bigger. The road to get to the office was too bumpy and dangerous... and I didn't like the gate to get out (by the car park).*

Andy was concerned about access problems because it was a daily experience in his life. If I went to an office on my own, I may have noticed access issues, but perhaps not in so much detail.

He also questioned the lack of 'decision meetings'. Although these meetings did happen they did not occur on that particular day. Because of this sort of assumption it proved important that we analysed the data as a team, because it enabled the wider picture of a group to emerge. Indeed, this benefited us all, because acting as a team gave us many more perspectives than a sole researcher.

Andy's style of interviewing was very gentle, and effective. He gave space for people to take time to reply. The response he had from people who were interviewed was very positive. I later pointed to Andy's relaxed approach and encouraged the rest of the team to give more space in their interviews than perhaps they naturally would. In this way we could learn from each other's 'best practice'.

Andy became tired earlier than the other team members did, so it was important that he organised his interviews earlier in the day rather than later. He also found he needed a sleep between returning from the office and dictating his fieldnotes. This point highlights again the need for planned research around people's particular needs and requirements. This is, of course, harder to organise in a team than if a person researched alone. By the time we went to Group D, Lou had taken over the role of writing Andy's dictated fieldnotes, although I still went back through them and asked him further questions.

I had specifically asked the team to be reflective about their roles. In her fieldnotes, Lou reflected on the activity of Malc and Andy as well as herself. She stated:

Andy and Malcolm did a good job again although Andy didn't say much at lunchtime when I ask him if he was alright - he said he was observing. I noticed him observing things in the room and also things outside like an ambulance in the street he was giving me a running commentary of what was happening. Malcolm did a good job observing and so on. I have to say how pleased I am on how well they have both done as researchers because I have done it before and knew what to expect. Lou fieldnotes May 21st 2002.

Summary points:

Andy referred to his own experience in order to understand what it would feel like to be a member of a different group. He was very respectful of the people we met and was open to learning from what he discovered during the interviews. Andy was a very gentle and sensitive interviewer, and those who worked with him reacted well. He had a knack of getting people to feel relaxed and able to talk. He gave people a lot of space. Andy found the days to be long and needed to rest during different stages.

Lou as researcher

Lou had more experience of research during the project as she was available to take part in the fieldwork at all of the groups apart from Group A. In Group B she was able to apply the knowledge she had gained at Group C, and inform the others of what to expect and how to go about some aspects of the research. As the work of the team progressed, Lou took a more active role in research support, not because she was asked to, but because she was genuinely interested in how the team was working and wanted to take on further tasks. In this way Lou modelled her role on the roles Niall and I had in the group. Lou's fieldnotes were generally more detailed as she was able to type quite quickly and did not need to rely on dictation. Here was an example:

After arriving at the Group B office, at around ten-ish, we sat in and observed a meeting, which was going on with two People First groups. Unfortunately a third group were unable to make it. I facilitated the meeting while Donna, the project manager, decided that people would speak more freely if she were not there. There were lots of people there. Everyone was very interested in what we are doing and asked lots of questions. They said how much they enjoy their work and like the supporters they work with.

Note how Lou said we observed a meeting, when in fact her role was actually that of facilitating the meeting. She moved from participant-observer to facilitator-observer.

After a break Rohhss facilitated a meeting about supporters, while Andy and I sat in the other room. Unfortunately we couldn't read the material because it was in small print. This was while Malcolm and Niall were having a look upstairs. One thing I did notice that Brenda is very small, even smaller than me, which is saying something.

After having a buffet lunch, which was very kindly provided, I

interviewed Charles. He had a lot to say, but because of his accent and speech difficulty I found it difficult to understand him.

My thoughts are I preferred yesterday to today because we did more yesterday whereas today I sat around more observing, although it was nice to meet people and I have agreed to keep in touch and let Donna know how my exams go.

The relationship between Lou and Donna had shifted from researcher/ researched to an interest in her personal life. Lou later commented that she and Donna had a long discussion about 'Neighbours' and other soaps they both watched on TV. This 'informalising' of the research process seemed to be particularly evident in inclusive research.

Rohhss and Niall supported us well and helped to set up the tapes and so on. I have really enjoyed this field trip so far and thanks to Rohhss and Niall for their support as always. Lou fieldnotes May 22nd 2002.

The team's appreciation of the support to do the fieldwork was ever present and I believe they all thoroughly enjoyed the experience.

Although Lou carried out more interviews than the others in the team did, she was inclined to feel awkward if a response was slow or the question not understood. On these occasions she showed a tendency to rush. Andy and Malc's approaches were different. They were more relaxed, and because of this they could get more detailed information at interview, whereas Lou got more details into her fieldnotes. Lou was reflective of this to some extent, in that she was aware that it happened. Of course, it was also to a large degree dependent on the person being

interviewed, but she did not seem to bring those thoughts into changing her own approach, which could have made a difference:

After this I interviewed Brenda. This was also difficult because she answered the questions but didn't expand so the interview was over too quickly.

This implied that Lou was following her list of questions rather than flowing with the interview and probing further. Andy managed to do this but then he wasn't reliant on the interview question sheet, being unable to read it. He would exhaust a question and then ask for a reminder of the subject of the next question from a supporter. Lou was keen to get on and do her interviews alone, without any support. Looking back, it seems likely that she would have benefited from some support, at least until she had seen the difference an alternative approach could make.

Although we had discussed in the group the issues that may occur with interviewing, it did not seem to counteract Lou's discomfort with silence. However, she did seem to allow a little more space by the time we did the last set of interviews in Group E. Being comfortable with silence, asking for repetition when it is hard to understand what is being said, and explaining the meaning of questions to someone finding the ideas difficult to understand, can all prove taxing to a researcher. Arguably it was more difficult to interview members than interviewing a typical advocacy support-worker because of the wide variation in people's needs.

Summary points:

Lou was keen to develop her research expertise into all facets of the research process. Her role shifted between researcher, supporter and teacher within the group as she provided assistance to Malc and Andy and the rest of the team through reading articles and taking dictation. Lou was not keen on observation but this was largely due to her sight difficulties. Although she did not tend to probe at interviews, she was very interested in the supporters and was quick to build up rapport.

Differences in Research Approaches

Each of us had different approaches to research. Indeed, this was one of the attributes of a team approach, that different styles could complement and enhance the process.

Summary points:

The overall value of the team approach was that it gave us the unique ‘insider’ perspectives on both the support-workers and the members. Also, because we had all been involved, it made the analysis of the findings a rich and interesting discussion, as everyone had a different perspective to bring to the sessions. We gained so much more information through using a team approach, than we ever could have done with a lone researcher. IPA may benefit from being adapted to use in teams.

However, I was concerned that some of the situations that occurred did not lend themselves to an open process, which is why, for example, I took the decision to facilitate the groupwork around support on my own in Group B. I felt that the team would lead the information gathered if I did not engineer to work with the group alone and find their own views. At this point I was more interested in

ensuring the quality of the research findings, than in further developing the inclusive process. This suggested a content versus process tension, which, in hindsight, needed some analysis.

On reflection it may have been a mistake to assume the findings would be flawed. I could have approached the task differently. It was something we could have discussed and come back to with a different approach. It would have been beneficial to have more time to deal with these issues on site, but time was at a premium during the fieldwork process and the days were generally exhausting.

Comparisons

During the fieldwork I undertook some interviews with members, and Lou undertook some interviews with supporters, in order to compare the process and findings.

Lou's interviews were very much shorter than mine, adhering closely to the interview sheet. Generally her approach was to get the support-worker to answer the question without much expansion. In contrast, my interviews tended to be rather lengthy. I was not concerned with gaps and silences and often probed further around the ideas that were expressed. This approach, however, did lead to long hours of transcription. On the other hand I needed the detail for the intensive analysis I had planned for the support-worker interviews. A third factor in Lou's interviews was that the support-workers might not have felt so much at ease speaking to a group member as to someone they perceived as a fellow supporter.

My interviews with members were difficult to compare because of individual differences and levels of communication. Again my interviews tended to be longer as I probed more around the questions.

It should be said that the interviews with members were not always easy to conduct and gave many challenges around effective communication. This was especially the case in Group E, where the difficulties were further compounded by the differences in people's accents, the use of unfamiliar words and phrases and the fact there was background noise. We had been unable to get a separate room for interviews. It was, therefore, unsurprising that the team came round to express the views they had about the importance of 'person-led' and 'person-focussed' research, (Carlisle People First Research Team, 2004), that took into account different individual needs and preferences. This was a theme important to team members the whole way through the research topic and the research process.

Supporting Research – Niall as supporter

Niall's support role was very specific and tended not to stray too much into other areas of work. He was very clear that he had a job to do supporting the members of the team. Like his job as an advocacy support-worker at Carlisle People First, he conducted himself in a 'background' manner, waiting for his instructions from team members and then attending to the support needs required. A lot of his work was around making information accessible, for example explaining jargon, as well as supporting Andy on a one-to-one basis.

This process of support was very similar to the support he provided back in the office in Carlisle; it was just that the subject was different. He did not put forward his own ideas into the planning in either location; he would wait until everyone had their say before any comments were made. He endeavoured not to pass opinions about what was happening when we were in the field. Niall has written about his role in Chapman and McNulty, (2004). There were many commonalities between Niall's role in the self-advocacy group and Niall's role in the Research-team.

Supporting Research – Rohhss as Supporter

My role could be similar to Niall's at times, specifically when I was supporting a member of the team to conduct interviews or facilitate a group. At these times I mirrored the background support role Niall used, fielded questions and gave attention to the team researchers. I also occupied the same role as Niall when we were supporting the team in their History-Workshop, because that was about their work over which they were taking ownership for themselves. However my role changed back and forth within the research process and I developed an awareness of when these changes occurred and how they affected what happened subsequently.

Because I was also a researcher, I did have opinions and I did have a voice. I believe this pointed to the greatest differences between the role of self-advocacy supporter and the role of researcher within an inclusive group. I took part in the planning process and, furthermore, I had my own particular area of research: interviewing support-workers, facilitating groups, looking through documentation

and acting as an observer. I also took on a team leader role so, in this particular project, I led the process of research through the whole cycle. This could be construed as my control over the project or my exploitation of others. However, as a trained researcher I could give guidance and leadership and be open to the development of other peoples skills, gradually reducing my own input. This I tried to do.

One important aspect was not to put my opinions first. I was keen to find out what the team thought before I put forward my own ideas as I was aware that if I spoke first it could lead and influence the other people in the team. Although I was a researcher and a team leader, I also relied on techniques I had learned as a supporter in order to give space to other members of the team.

I have endeavoured throughout the project to be inclusive wherever possible. For example, as a team we were involved in a number of presentations where I provided background support and occasionally had my own part to speak. We also wrote articles together for books and journals, and presented partnership papers at an international conference in Melbourne.

Summary points:

Niall and I had worked together before at People First, and were aware of our different approaches. Generally, my support was based around knowledge of research issues as well as general support, whereas Niall's support was more general. His support was far more led by the team members, as he had come to the group as a novice. In this instance the team knew more about research skills than he did.

In this way each member of the team had brought a different set of skills to the team, though some may have overlapped.

Analysis

After the fieldwork visits we would spend a few days apart and then meet to have a debriefing session. It was also an opportunity to let anyone in the team who had not been to the site hear about what had happened. This reporting back was always interesting because absent team members asked questions about the group that had been visited. That would set us thinking about the analysis process, and later, making some comparisons between each group (see Appendix 10). During the post-fieldwork phase I ensured that all the notes were written up and all the other evidence from paperwork was collated. Each visit involved the taking of photographs, which then had to be developed and shown back to everyone. We also wrote a 'thankyou' letter to each group to express appreciation of their hospitality and time. Lou tended to take on this role for the group. Basically this phase was about tying up loose ends and preparing for data analysis.

The literature on methodology (Chapter 4) indicated that data analysis was often a part of the research cycle that people with learning difficulties were excluded from (Minkes et al, 1995; Stalker, 1998; Ward and Trigler, 2001). We tried different approaches to analysis to see which suited us best as a team. Generally, more of the team were present at the analysis stage than during the fieldwork. This worked quite well because it gave a fresh and open outlook to the information being scrutinised.

In the case of Group B we organised six analysis sessions. The first took place in a room at the museum in Carlisle, which was accessible, and where we could pin all our work on the wall, use flipcharts and display the photographs. During this meeting we first went over people's recollections of what had impressed them about the group and what came to mind the easiest. We then tried to list and prioritise what team members thought most important. This required some intense facilitation, as, at the beginning, it was hard for the team to work out exactly what it was we were trying to do. This was not surprising, as they had never really gone through this process in such a way before.

Although Niall and I facilitated this groupwork between us, I also added my own ideas and reports. When we had compiled a list we went back over it to think through the points being made, to consider why they were important, different or relevant and what they told us about the role of support. From this process, themes began to emerge as described in chapters seven and eight. This process is set out in the Appendix 10, to make explicit the line between evidence from data collection and interpretation.

At the second meeting we looked back over the photographs as an initial reminder and added more information to each theme. By the end of the second meeting we had tightened up on the themes, but these had all come from the fieldwork notes and people's memories. We also had to take into account the themes that the team had expected to emerge, to see if they had.

The third meeting focussed on listening to some of the interviews that members had conducted. We played the interviews back on the recorder and stopped occasionally to discuss what was being said and what we thought it meant. This was either noted under pre-existing themes or seen as emergence of other themes. The fourth and fifth meetings were also about listening to tapes. By this time Niall and I had copied the tapes so people could take them home to listen to at leisure. I was also busy transcribing tapes ready for the next session. I already had the transcription from my own first visit to Group B and we listened together to an advocacy support-worker's interview.

After the fifth session the task of analysis had become laborious for the team and other interests were beginning to take over. People's own projects were also being discussed together with work for the Melbourne presentations²⁹ and an article we were writing, all of which were pressing on the time of the team.

The sixth meeting was about agreeing the main themes and these were mostly from the fieldwork and the tapes of members' interviews, as well as any interview a team member (apart from myself) had done with staff. In the case of Group B, this was Lou's interview with Donna and its comparison with mine.

We also spent time reviewing and thinking about how we could make the process easier the next time round. As mentioned earlier, it had struck me that transcribing was time consuming, especially given that transcriptions were inaccessible and of no relevance at all to the team. We were much better off just using the tapes for our analysis work, even though this meant making at least three

²⁹ The Research-team presented four papers given in partnership at the Inclusion International

extra copies of each tape. It worked better when people took the tapes away and listened to them during the week so that we could discuss them at the next meeting. However this was not always possible and so time was spent at meetings listening together. Eventually the interviews were transcribed with the assistance of Lou, who as I mentioned earlier was swift at typing and wanted to take on more of a full researcher role.

The process of analysis for the other groups was easier because it generally involved fewer people and we had already worked out a routine. Lou and I had visited Group C and because we spent time together transcribing the tapes we could work more efficiently on the themes. Group B was in effect our template, which we came back to with themes from other groups. Most of them already fitted although a few new ones emerged.

By the time I had transcribed my own interviews with advocacy support-workers, analysed them thoroughly through the process akin to IPA, and discussed them with the group, we were armed with our main selection of themes and issues to use for the writing up.

The team approach also nurtured an implicit form of triangulation. This was based on the different levels of analysis using aspects of intentionality (what the team had predicted the themes may be) laid beside detailed interpretation (what was actually found and interpreted from the findings). Indeed the team aspect could perhaps be developed and added to an IPA approach. Because of the very

focussed interpretative exercise demanded by IPA, a team discussion could add clarity.

Summary points:

Some of the lessons we learned about team analysis were:

- The importance of having a discussion soon after the fieldwork event while the experience was fresh in people's memories.
- To have a clear plan about what the agreed team intention was for each session; that is; breaking tasks down.
- Not to allow a session to go on too long because of possible lapses of concentration - analysis is hard work.
- To focus on the availability of tapes and photos for team members to take away with them for their own thinking time.
- To prioritise what needs to be done as a team, and get that done first, because if the process is too lengthy people start to lose interest.
- To change around the method of working so that people maintain interest.

It would probably be less time consuming to listen first to the tapes and highlight the more interesting, relevant parts for team members as there was so much information (see Mitchell, 1998; Williams, 2002a). However in doing this, the decision making of the team as to what was relevant and interesting would be lost, and so I chose not to follow this precedent. Even playing the tapes that were difficult to hear and decipher was important because it led to lessons about interview style, the importance of private rooms and avoidance of background noise. In the end there were compromises to be made between quality, inclusion and time. Luckily a three-year project afforded us the time at this juncture, but clearly in other contexts this may not always be the case.

Practical Issues

Niall's role was invaluable because it would have been impossible for me to provide the necessary support to the team alone, particularly in Group B, but also during analysis. It also enabled deeper reflection. Niall was unable to attend the fieldwork in Group D and working there supporting Lou and Andy alone proved to be quite taxing, especially as Andy began to feel unwell on the visit and needed quite a lot of physical support.

When we visited Group E, I supported Andy, Lou and Malc alone. This involved a lot of travel by both car and ferry. Malc got the 'flu as we travelled over on the ferry and was then unable to leave his hotel room for the duration of the visit.

This was not at all ideal. I needed to support Andy and Lou and travel out to meetings, whilst at the same time worrying about how Malc was getting on back at the hotel. We kept in touch by mobile phone and luckily the advocacy support-worker (Isaac, Group E) helped us out in practical terms. However, the situation was highly stressful as I felt unsupported myself, being away from home and feeling responsible for other people.

Because we were a team, when things did not go to plan, we would generally sit together and discuss the issue and reach a shared agreement on how to proceed.

This we did with the situation on our visit to Group E. In the end, rightly or wrongly, when we were away from Carlisle I felt responsible for the welfare of the team, and that responsibility was obviously more comfortable to take when sharing it with Niall, as we could provide back-up for each other.

Even practical issues, such as having knowledge of first aid, became important. There were grey areas to think about around liability and responsibility; many aspects that are probably not common to other types of research.

Providing support in these situations involved research support plus all the aspects of assistance that are common to group advocacy support-workers on a visit away from home. A blurring of roles is inevitable when you are working side by side, sharing a bedroom, travelling and spending whole days together. We talked about the idea of 'porous boundaries' where nothing is really set in stone, but managed on a moment to moment basis, in fact very much like an image of the support role in self-advocacy.

Sometimes there were tensions between team members to deal with, differences of opinion, personal problems or upsetting news from home. The experience was satisfying but also extremely intense. I would be wary of entering into it without the background knowledge we all had of each other prior to the visits. I cannot overstate the necessity of knowing about each other and how valuable that was both in the context of this particular piece of research and our subsequent visit as a Research-team to Melbourne, to deliver the collaborative papers at the International Conference.

Summary point:

All of these experiences led me to understand that adequate support funding is vital and that, in general, more support is probably required than one would initially plan for. Contingency plans should be made.

Accessibility

The points around accessibility in order for the Research-team to work effectively were apparent at every phase and in a variety of ways. This mirrored the findings about the role of support; that accessibility was perhaps the most important issue if knowledge is to be shared.

Much of the work in the team, particularly in the planning phase, has been based on graphic illustration (see Appendix 9) because the written word was not an effective means of communication between us all. I noticed this has had an effect on me, where now I have a tendency to imagine a picture in my mind when thinking through a concept. It is as if this skill has developed in my own mind through the amount we have used it in the Team, perhaps similar to learning a foreign language and thinking less about each word as one comes naturally to access the words in one's own mind.

When I supported the Research-team I drew pictures on flipcharts using 'easy' words to capture the ideas people in the team were coming up with. Andy, being Scottish, disapproved of the phrase 'plain English', and has asked us not to use the term. Graphics and discussion were the main areas of communication in the group work of the Research-team.

Regarding the thesis, the team agreement was for me to write-up the whole project, then co-design an accessible version (omitting the more academic aspects), to give back to the team for dissemination to the advocacy groups. Frankly, the formulation of a thesis to be examined was immaterial to the team;

except they know it has been an important aspect of my life keeping me away from working at People First. Andy informed me at the beginning of the project, when we first discussed postgraduate research, that in his view an inaccessible document would be a pointless exercise:

Andy said a thesis that was big would be useless. He said people needed words made big. Malc added that things needed to be pictorialised. I explained that bullet points would not be enough to hand in for a thesis.

(RG meeting notes: 9th November, 2000)

The situation was slightly different for Lou, because we had worked together in partnership on other projects. She has become involved in further aspects of research work, because of her ability and desire to read what I am writing. Because of this Lou agreed to read each chapter and provide a ‘jargon alert’ so that I could endeavour to use clear words.

By the time the accessible report is given back to the team, changes will have been required. This is because in all the publications co-written with the team I have been asked, particularly by Andy, to change the way I have explained ideas into ‘easy’ language (see Chapman and McNulty, 2004 and Carlisle People First Research Team, 2004). This is difficult to do at times but something that becomes easier with practice.

The completed thesis is my own writing up, unedited by the team, but checked for unnecessary jargon by Lou. Ideally in an inclusive project, it would be co-written but currently this is impossible in the context of a thesis.

Similarly the plan of the team is to report back to the groups we visited when the accessible version is available. We intend to organise a workshop for the five groups involved to look at the main issues around support and consider together with the groups how these issues could be addressed. Following this, the information will be made available for the Carlisle Research-team to develop a training pack around the role of advocacy support-workers. This will be used for training and development purposes with other groups, and hopefully will provide some much needed income for the group. Again this fits Walmsley and Johnson's (2003, p.64) second criteria of inclusive research:

- It should further the interests of disabled people; non-disabled researchers should be on the side of people with disabilities.

Conclusion

This chapter has focussed on the process of a team working together inclusively on a research project. I contend that there is no part of the research cycle that cannot be made accessible. However it is vital that people interested in research have training in research skills so they are not thrown into tokenistic roles.

Research supporters need to be fully aware of access issues and methods to help overcome barriers. They also need to be mindful of the myriad of practical issues that may come to the fore.

Inclusive research here was based around the individual team members' needs, abilities and preferences. Working as a team has helped this process to happen as people's strengths and weaknesses have complemented each other to work as an

effective whole. A team has to be properly funded, supported and facilitated. In order to begin on this task it was vital that the team had gelled, knew each other and understood how each other worked.

Working as an inclusive Research-team was a learning process in itself. This project has emphasised some of the highlights and pitfalls. If the team were to start the project again, it would be different, because we have all learned lessons about what has worked well and what is difficult.

Further projects will be decided by the team and carried out in the way the team decide to do. Of all the types of research people could be involved in, someone else's thesis probably affords less chance of real ownership and control. This is why this particular project experience became overlaid with agreements around other projects. The benefit however is that the post-graduate environment may be beneficial in terms of time and support for developing and testing ideas. Other projects for the Research-team are currently being planned, and one has just received funding.³⁰ A discussion of issues looking toward the future will take place in the next chapter.

CHAPTER 10

CONCLUSIONS

This chapter summarises the whole thesis, including findings from the project around:

- a. the role of the advocacy support-worker
- b. the knowledge gained from working in inclusive research.

I explained in chapter 4, that I believe the process issues of this research are of great importance, but not in a way that should overshadow the outcomes of the actual research. Therefore questions are raised about the future direction of self-advocacy support and also of inclusive research. I have reflected on facets of the project I have learned from and would approach differently in the future, also noting some questions for future research.

a) The role of the advocacy support-worker

This research project was designed to answer the following questions:

- 1. What are advocacy support-workers' perspectives of their role?
- 2. What are People First members' perspectives of the support-worker role?
- 3. What light does this shed on the purpose of self-advocacy groups?

³⁰ The Research-team were successful in a bid to the Heritage Lottery Fund's Awards for All, (September 2004) for a three-month pilot project on 'Self-advocacy and Autism'.

The intent of these questions was to build on the work of Wilson (1997), Goodley (2000) and Walmsley (2000), in particular, analysing the varied and often hidden role of the advocacy support-worker.

What was already known about the self-advocacy support role

The research showed that ideas of self-advocacy were high on the government agenda (*Valuing People*, 2001). However there was little to indicate the significant role and position of an advocacy support-worker. It was a hidden role (Walmsley and Johnson, 2003) and therefore could not be scrutinised or held to account.

The history of advocacy support-workers illustrated the importance of the early ‘champions’ in assisting to establish self-advocacy in the UK (Williams and Shoultz, 1982). There was evidence that the role had since shifted from voluntary ‘allies’ to paid members of staff. This implied that the relationship between members and supporters had changed and that, ostensibly, the employers (people with learning difficulties) would be likely to have more control over what the workers did, rather than simply accepting benevolent assistance (Wolfensberger, 1999).

However there were indications, going right back to the inception of People First in the UK, of tensions between supporters and members of People First groups (Bright, 2000; Hersov, 1996). In recent years there has been a small but growing critique from people with learning difficulties, suggesting that support-workers need not ‘take over’ (Bright, 2000; Lee 2003a), and could be more aware of where

‘real’ power issues lay. That was, outside the confines of services and individuals’ lives, to power-maintaining structures within governments, policy and law (Aspis, 2000).

Therefore the research sought to uncover how workers dealt with issues of power. This raised a further question over how they could be transparent and open to reflection, yet support in a ‘background’ way (Sutcliffe and Simons, 1993). The obvious challenge was how to support effectively without ‘taking over’ from members of the group, thus enabling the process of empowerment to take place. It was evident from the literature that the lack of grounded empirical data over the support-worker role needs to be addressed.

The position of a person with learning difficulties, in terms of current disability theory, was also highly contested and complex. The importance of people articulating their own ideas of what was meaningful and important to themselves, and establishing their own position in the broad realm of disability rights, was timely. What was evidently missing was the voice of people with learning difficulties generating their own theories and ideas. This added to the necessity to research the perspectives of both group members and their supporters. This, then, was the position the research emerged from.

What the findings suggested

I will now turn to the major findings of the research by working through the specific questions asked:

What are advocacy support-workers' perspectives of their role?

The research showed that the self-advocacy support role was an inherently ambiguous and contradictory role. Although there was apparent energy, enthusiasm and commitment (see Chapter 6) it was shown that this needed to be harnessed and channelled into effective means of providing support, if a group was to adhere to their own rhetoric around 'People First philosophy'. Many of the workers appeared to be busy 'doing their own thing'. This was largely without reference to the ideas and requests of their employers (see Lesley, Group A; Donna, Group B; Ian, Group C; George, Group D). A conclusion from the research was that there was currently no expectation amongst support-workers that their roles would be taken over by people with learning difficulties, which strayed from the earlier ideas that 'advisors' would eventually 'work themselves out of a job' (Dowson and Whittaker, 1993; Worrell, 1988). Therefore advocacy support-worker roles were likely to be enduring and as such, more imperative to be studied and called to account.

As a consequence, there were some important points to uncover in regard to the views workers and members had of the advocacy support role.

The overarching issue of 'communication' came to the fore as evidenced by comments made by some of the workers (Group A, C and D). The research showed it was vitally important for workers that they:

- Knew and understood the plan of where the organisation was going (what was wanted to be achieved in the bigger picture).

- Were aware and could respond to the individual needs of the members they worked with.
- Practised critical reflection over power issues within the organisation, at all levels, which included communication and accessibility issues.

There were two main contradictions occurring in self-advocacy support revealed by the research. The first was that individual needs required to be addressed (individualised support), if the group was to adhere to the ‘People First’ rhetoric. This was a pivotal aspect of the groups because the support-workers, on the whole, were in congruity with the idea of ‘People First philosophy’. However, this often conflicted with the wider aims of the group (group support) in terms of time and resources. Yet if these individual barriers were not addressed, the members were not in a position for empowerment to happen and to take control, which blocked a wider view of where self-advocacy could lead (see Yvonne, Group A; Isaac, Group E).

The second contradiction was that support-workers supported the very people who managed and employed them, thus creating a largely unique and uncharted position for both parties³¹. This double role was a significant point of tension for the advocacy support-worker, and underpinned the necessity of ‘trust, respect, loyalty and friendship’ (Geoff, Group A). This, then, was no ordinary job, but one of multiple roles, where boundaries were blurred and trust and friendship given generously, by those in a personally vulnerable situation (Booth and Booth, 1996).

³¹ There are some similarities with personal assistance and live-in nurses or servants for people who are old or ill, but they are not also helping individuals to run organisations.

Perhaps it was unsurprising that the job descriptions failed to give a true reflection of the tasks and role, because the role, being ambiguous, was so difficult to define. The complexities of the advocacy support role were also unacknowledged in other official documentation of the groups (e.g. policies and procedures, see Chapter 8), often borrowed from other organisations (Groups A, B and C) with different ideological foundations. This allowed problems to arise, ironically set up by the organisation itself. The research suggested it was vital that all the different parts of the organisation hung together (such as around accessibility and inclusion) as a coherent whole, if it were to reach its own stated goals.

There were also tensions between the reality of who was managing the group. This issue was particularly crucial because of employment law and other pressing legal responsibilities. Often this area of control was denied (for example Group D employed a support-worker as ‘company secretary’). It could be suggested that an essential facet of ‘empowering’ support would have been to give assistance to this important area of director or trustee and/or management committee control. Instead, the research revealed that advocacy support-workers fulfilled these roles (Groups A, B and D) and thus blocked learning, ownership and control by the members.

Through all of these contradictions, the advocacy support-worker was seen to put themselves in a number of multiple roles that required constant and vigilant reflexivity. Without this reflexivity it was highly probable that supporters would ‘take over’, and therefore the group would not reach what it set out to achieve. This was the exact complaint of writers such as Aspis (2000), although, because

there was no empirical research of the role, she may not have been aware, at the time, of the quantity of conflicting tasks being asked of the support-worker.

Maintaining a high level of reflexivity was evidenced through the interviews in surprisingly many cases, and was a great tribute to the commitment of the workers. It was, however, hard for them to do this without effective supervisory and training structures, which, in the main, the groups simply did not have. A way forward was suggested at the end of Chapter 8.

Despite all the problems and complexities to deal with, most of the advocacy workers enjoyed their jobs and two-thirds intended to stay for the foreseeable future. This, in part, answered Goodley's (2001) question about whether advocacy support-workers would work themselves out of a job.

What are People First members' perspectives of the support-worker role?

Prior to the research there was no guidance from members, apart from the work of Aspis (1997; 2000), and some comments in Goodley (2000) that informed what members perceived as the advocacy support role.

It was difficult to define what members wanted en masse from their advocacy support-workers because each group was different and made up of different personalities, needs and expectations. However there were some common issues.

What became clear through the research was that the opportunity to learn through experience was crucial (Martha, Group B; Emma, Group D). In working at this level, barriers of accessibility had to be confronted for each individual in a person-centred manner. Members wanted their workers to assist them so that they could achieve their own goals.

One of the problems that arose for members taking on tasks and some of the roles of a supporter, were that, on occasions, their peers would resist their role, leaving the person feeling humiliated (Charles, Group B). This may link into complex issues around identity (Finlay and Lyons, 1998) that would benefit from further study.

These issues, in turn, gave rise to the tension between the needs of the individual as opposed to the needs of the group as discussed in Chapters 6 and 7. Geoff (Group A) was certain that supporters should know that self-advocacy was about a social movement, and then they would know their task. This task was being taken on in Group A, but the effect was problematic because the members did not appear to be ready for it. Certainly none of them, apart from Geoff and Gemma, spoke about it.

Setting the scene for effective self-advocacy, in terms of what the membership wanted and needed (in their view), was arguably the role of the advocacy support-worker. That is, for the supporter to understand that it was a facilitative rather than leading role (Geoff, Group A). Future study could focus on the reasons why members leave their People First organisations. It would be interesting to find out

if it is because the members' needs were not being met (a negative reason), or whether empowerment moved people on to new and different experiences (a positive reason).

A large part of the task of the support-worker was seen by members to be the making of accessible information. Gemma (Group A) had been distinctly clear that if members did not understand what was happening, then the support-worker was responsible. This was a significant finding. In this way it could be suggested the role of the advocacy support-worker was to work out how to bridge the gap between the (largely inaccessible) outside world and what members wanted to do for themselves. The vehicle to bridge this gap was effective communication, allowing access to knowledge and information.

Crucially, this also implied that issues of impairment could be counteracted by the support-worker, enabling the members to proceed without stumbling over the constant barriers that were around them in everyday life.

The research also showed that what members wanted from workers was so wide-ranging that it essentially became contradictory. Members wanted protection (see Emma, Group D), but also no interference (Gemma, Group A); management (Martha, Group B), but also ownership (Geoff, Group B; Luke, Group E).

Members spoke about how they were in control of the groups (Felix, Group C), but did not seem to be aware that a lot of the decisions over how the organisation ran were out of their hands (See Group A, Chapter 6). Members did not want

support-workers to ‘take over’ but nor did they want the ‘total power shutdown’ described by Dowson (1990).

Many of the workers were highly skilled, for example in management and teaching skills, whereas the members had experienced little opportunity to gain skills and qualifications. Arguably these skills were (or could be) put at the disposal of the groups, just as positive role modelling also had a place (Jayne, Group B).

The concept of re-inventing the wheel (Ian, Group C) was a significant way forward for members to begin to take over some power and control of their groups, especially if the issues around identity could be discussed, understood and addressed. Again this could imply further study.

What both sets of perspectives indicated about the advocacy support role

Although the role of the advocacy support-worker was complex and challenging, the nature of its scope and porous boundaries also allowed for creativity. Indeed this idea of porous boundaries reflects well the different portrayals and challenges of the support role described in Chapter 3; for example; Clarke (1992) on support versus control; Wolfensberger (1999) on support versus judgements and Bersani (1998) on framing identities versus facilitating self-esteem. Equally the tension of the social model versus SRV brought out the challenge to normality versus replicating norms in addition to the issues of personal issues versus the collective. Goodley’s (2000) view that advocacy support-workers may well adhere to a model of support without consciously being aware of it, embraces the notion of inherent

contradiction. This, of course, appears to fit well the contradictory expectations of members.

The support-workers in interviews (Jayne, Group B; Gordon, Group D; Isaac, Group E), also expressed facets of these contradictions. It was revealed that workers who adapted to the difficult challenges and found their own place within the work felt the role hugely rewarding. In some ways the blurring of boundaries allowed the worker to feel part of the 'movement' themselves and to become released from normative 'professional' (service orientated) expectations around them (Moir, Group A; Ian, Group C; Gordon, Group D).

These normative expectations, the research showed, were ever present in the demands from contracts with local authorities around representation of members from self- advocacy groups on local Partnership Boards and other representative committees (Groups A, C and D). This showed another major contradiction between the 'grassroots' (chosen) work of the organisation and the work that had to be done to fulfil the service contracts. Precious time and energy were being taken up, reportedly more than was being paid for (Group A and C), and in an inaccessible manner, resulting in less time to work meaningfully with members. Whilst *Valuing People* (2001) and other national initiatives provided some much needed funds, it appeared from the research that these policies have also imposed implicit restrictions and complications on the activities of the groups, (with a growing emphasis on proving 'outcomes'), which they were starting to resist.

Walmsley (2004b, p.66) states, 'there is no question that most people with learning difficulties need support to lead fulfilling lives'. The support in People First groups appears to be aiming to do this, to involve people in experiential growth; working together to speak up and to run and manage organisations. Clearly support-workers and members share the view that they are trying to reach the 'People First' philosophy, but despite the hard work of those involved, the struggle to do so is immense.

Part of this struggle was due to structural issues such as paucity of funding (Groups B and E) and barriers that people with learning difficulty face to achieve an equitable lifestyle (vis a vis the social model). However part of the struggle was in finding out and communicating within the groups, exactly what it was that people wanted to aim for. One of the very positive findings of the research was that, on the whole, people cared deeply about each other and tended to foster friendship and concern. Harnessing this approach of friendship and partnership could help further establish collaboration between workers and members of groups.

What light does this shed on the purpose of self-advocacy groups?

There was clearly no universal template for a successful self-advocacy group. The research found that there were two different types of advocacy going on in the groups, one for consulting and having a say in services, and the other for the more grassroots People First model of self-advocacy, which was about what the members were wanting to do (Chapter 8). Advocacy was on the Government agenda (*Valuing People*, 2000; *The Same as You*, 1999; *Fulfilling the Promises*,

2003), and was officially regarded as an essential part of life. It was therefore surprising to find that difficult issues of funding were paramount to the groups, making their position precarious and fragile and taking up much of the workers' time. It was hard to make plans very far in advance, not knowing if funding would continue (Groups B and C).

Many groups, as evidenced, were based in poor quality venues and were overwhelmed by the time it takes to successfully receive funding from different sources (Chapter 6). Lack of funding portrayed a negative image of people with learning difficulties in their own organisations. Entering bleak, cold, cramped and poorly decorated offices (Groups B, C and D) was not inspiring. This point about imagery, an essential feature of SRV theory, is a reminder that bleak and cold places are not about people who are valued and admired.

Self-advocacy work, according to the advocacy support-workers interviewed, is not so much a professional role as a vocation (Chapter 6). To judge the role by normative standards may miss the point that increasingly, as we have evidenced, longer standing members feel this movement is likely to become more political and focus on challenge and change (Geoff, Group A; Felix, Group C; Emma, Group D). This is as opposed to helping people to 'fit' more easily into the system that currently exists. In some ways this also reflected the difference between service self-advocacy and grassroots self-advocacy mentioned above.

This shift reflected the theoretical influence and move from normalisation to a social model of disability, as espoused by Group A, though as Walmsley (2001) contends, there is still normalisation influence operating at an unconscious level.

The tension found in groups between protection and rights, was perhaps one of the most crucial of dilemmas. Because people have such different abilities how can any law, policy or guidance fit everyone's needs? There were different responses to this as made clear by the groups. The advocacy 'supported' and encouraged by the *Valuing People* (2001) framework had a tendency to inherently support facets of the organisations that fed into services, rather than challenge services and demand a different approach.

This research found that the People First model, if the ideal was applied, could bridge the gap between the personal and the political (for example, see Direct Payments discussion at Group B; development of women's group at Group C). The process of working to the People First model, recognised people's individual needs and characteristics at the pace they needed to be understood, whilst at the same time recognising the potential for the development of a social movement (particularly when these links were made clear, as in the examples above).

Group E gave an explicit example of the People First model in action. The members were aware of issues of power and the need for sensitive support. They understood that in a People First organisation it was their place to be in control (Luke, Group E). When they began to get organised, to get funding and an office, they talked about it together and decided they were not yet ready. No one took

control and filled in another funding form; it was left to the members to decide when they were ready. In terms of practical outcomes it may have appeared that this group had achieved little. However if the example is set in the context of lack of funding opportunities and the need for group members to be in control of the process, then perhaps it has achieved a lot. Contrasting this with Group A, where the social model was being imposed, the group had many activities and secure funding, but the position of the members was entirely different. The message from the research was that each group was different and required a pace that suited the individuals involved.

Many supporters and some members in the study believed national networking could happen right now, and there were strong views held by some of the membership about the future direction of the self-advocacy movement (Chapter 7). Bright (2000) felt, for example, that it had always been advocacy support-workers that had stood in the way of effectively creating a national movement by complicating the issues (Bright 2000). His comments were backed by some of the interviewees in the research (Moirra and Yvonne, Group A; Gordon, Group D).

This leads back to the point again that Gemma (Group A) made about the responsibilities of the support-worker if things were not working out for members or the groups (*'if someone can't understand things its because the supporter isn't explaining things well...'*)

Although People First National described itself as the national group, the research has uncovered that people feel power has not properly been shared from a grass roots basis. If this happens, in the future, with genuine representation, the groups

will be able to define their own ideas about a more global approach to the training of their support-workers.

This is a time to talk and discuss a national way forward, as there are evidently a number of people with similar views who want to start working together. As Aspis (2002) urged:

We've got to fight the bad fight and stop bickering amongst ourselves.

(speech at People First National AGM, Birmingham, July 2002).

B. The knowledge gained from working in inclusive research

The project was designed to answer the research questions in an inclusive and participatory way to help further understanding of the inclusive research paradigm.

So what, then, has this research discovered about inclusive research?

The starting point of the team's journey was a very different place to the point we have now reached, which in terms of the team, is only the beginning of the action stage of this project. From this stage on the research will become relevant and useful to the groups, as they will be able to use it, if they wish, to help train advocacy support-workers.

Major findings of the research process

The process the team learned about as they undertook the role of researcher during this study, turned out to be a journey of discovery, which led them to develop a particular style of inclusive research. This was because of their emergent

contention that research should be ‘person-led’ and not rejecting, (Carlisle People First Research-team, 2004), terms put forward by Elizabeth.

This style has evolved out of the necessity the group saw for counteracting ‘rejecting research’ and also because each person had strong feelings about what type of research should take place. It is built around the general practices people find helpful in their own People First organisation; that is, person-led, accessible, non-rejecting, experiential and holistic. The team will go on to describe and develop their ideas about person-led research elsewhere.

This implies a slight departure from Walmsley and Johnson’s (2003, p.64) framework, adding into it that, ideally, in the first instance **the research would be initiated** by people with learning difficulties, because it would be based around subjects which they felt were important. This is certainly the direction the Carlisle People First Research-team has since taken. It may well be different for other inclusive research groups, as they will be made up of other individuals who will be on a different journey. This finding mirrors the finding in the actual research, because of the importance placed on individuals and their access needs.

Another point of addition to make to Walmsley and Johnson’s (2003, p.64) framework would be that any research undertaken would **involve research training and development of skills**. I contend that it is not enough to ‘involve’ people with learning difficulties as their inclusion is far more empowering if they can develop their own skills and therefore lessen their dependency on research support. Lou illustrated this during the course of the study. Research training

needs to be provided for researchers with learning difficulties as Williams (2002) made clear. The problem is counteracting the lack of educational opportunities people have been able to access throughout their lives (see Docherty in Spedding et al, 2002). As the research has shown, this is sometimes part of what the advocacy groups are trying to achieve (see for example, Group A, B and C's training and courses). The specific individualised approach undertaken by the Research-team is not to deny that there are commonalities and themes around setting the scene for inclusion, participation and accessible methodology worth highlighting.

The detail of how to be inclusive and the choice of which methods and how to use them are developed focusing on what the research question requires. This then incorporates an individual's needs and preferences. For example, Andy needed to write fieldnotes, because the research question demanded a multi-method approach, but Andy also required assistance in the task.

Methodological rigour is an important part of the research task. I argue that inclusive research, rather than compromising the validity of the research, actually allows a greater scope for triangulation (enhancing validity) in different aspects of the process.

It is possible to devise a taxonomy of points relevant to undertaking 'person-led' research that may be built upon as knowledge develops further:

Taxonomy of person-led research	
	<ul style="list-style-type: none"> • Attention to methodological rigour • An emphasis on plain language and different methods of making information accessible • Access to information and knowledge • Experiential learning in a real context • The valuing of people’s own past experiences and different abilities • The use of groups and group work to support members with different abilities • Highlighting people’s own attributes and using each person’s skills to complement a team • The notion that all people have the right to be heard • A purposeful lack of imposed limitations and a space for creativity • Support as required for each person’s own needs • Support as ‘partnership’ or as a ‘bridge’ or in whatever context is decided upon by team members

Table 9: Taxonomy of person-led research

From the perspective of the Research-team these were the important points that emerged, or where there were distinctive priorities felt by team members.

Things that could have been done differently

If there were parts of the research that could have been done differently, it would have been to have more time in the field. In some respects this was restricted through finances and support, but it would have been beneficial for the team to

have more chance to relax into the role of researcher, and therefore to become more comfortable in the role. Participant observation and working in groups were particularly fruitful methods. Video may have been useful but also disconcerting for some of the group members who, in any case, found the tape recorder intrusive at times. Technical equipment could be useful but it was important to be aware, for example, that flash cameras could cause concern for people who lived with epilepsy. It was also important that any technical equipment needed to be within the bounds of use for the whole of the Research-team. This required prior training, an essential requirement of inclusive research.

Another area that would have benefited from more time, would have been to develop more accessible ways of dealing with the data for analysis. I think, as a team, through trial and error, we finally reached a place where it worked well, but by the time we established the process, people were tired. In future I would spend more time thinking about exactly what each individual needed, communication wise, in advance, to make the data most accessible for them. I would prepare it so team members could work on it in their own time, before coming back for group analysis sessions. Also, in this way, it would promote people's own independence as researchers.

Interdependency

This, of course, amplifies my own role as team leader of the research and the conveyer of research skills amongst the team. For all of the skills that could be taught, and all the experiential learning, it was still necessary for our team to have a skilled researcher at their disposal. Therefore, unless People First make major

efforts to fully train their own researchers, they may be in need of the skills of a research supporter (see comments from People First National, Chapter 5).

However, equally, we all needed each other, as inclusive research cannot happen without the team members. In this respect we were inter-dependent and could not have undertaken the task without each other.

Although I have been constantly aware of the limitations imposed on this study by the nature of its construction as a thesis, overall, I feel it did not undermine the learning about research for the team. Instead, within the team, it was used as a springboard to develop further ideas outside of this particular piece of work. In consequence the team has moved on to develop their own projects, where support was something added on after their own decision making process. This was in contrast to simply being party to this project, which was for them, at least at the beginning, someone else's research. The findings show it is essential for team members to have the opportunity and time to learn about research skills, through the whole process of research.

Without the initial setting up of this project and the participation of the team, the journey may not have happened because there would not have been the space or time created to allow it to take place. We have been able to spend three years experimenting, discussing and understanding how research can happen in a way that is meaningful for people labelled as having learning difficulties. For this we are indebted to the space created by the Open University.

Separation of roles

Looking back on where this research started from, I contend that there is a distinct separation of the researcher and advocacy support-worker role even if the researcher is within the group to support research. The research supporter leans more toward a partnership model (see Wilson, 1997), where it is apparent that knowledge and skills are brought in from the outside (academia) to put at the disposal of the team.

The difference from emancipatory research is around issues of whole process control. In emancipatory research, although disabled people themselves are not precluded from being researchers, it is quite acceptable for non-disabled researchers to undertake projects, as long as the organisation stays in control. However, one of the defining aspects of this piece of research is that it has attempted to be inclusive in all respects. This challenges previously held views that some aspects of research were 'beyond' the inclusion of people with learning difficulties as researchers (Clement, 2002; McClimens, 1999; Mitchell, 1997; Stalker, 1998; Tsuda and Smith, 2004). As long as time and accessibility can be properly addressed then there is a part each person can play whose own personal journey leads them into a researcher role. In many ways this assertion mirrors the comments of Gemma, (Group A), that inclusion is largely the responsibility of the (research) supporter.

Like the advocacy support-worker, the researcher has to be aware of the tendency for blurring of roles and make clear they are conscious of which role they occupy

at which time. The change of role is difficult, but not impossible, and the more it is discussed and analysed, the easier it becomes to take note of the differences and improve practice. If there was funding available, the roles could be separated out and occupied by different people, to help clarify the differences, but this is not currently feasible as shown by the paucity of funding within the groups studied.

Models of Research

In academic language, the research is leaning towards emancipatory research, because of it being controlled (to a great extent) through the whole process by disabled people, but has various departures; not least because it is using language that the people involved in understand themselves. This point was made by Walmsley and Johnson (2003) which they incorporated into their definition of inclusive research.

In some respects this research has shown that the term ‘inclusive’ may need to be broken down to actually reveal what is happening within the research process, certainly to ascertain the extent of people’s inclusion.

The findings of the research suggest that emancipatory research, whilst obviously being a powerful tool for the disability movement, does not quite reach into the current experience of people with learning difficulties as researchers. Apart from the issue of accessibility, people with learning difficulties are (with only very few recent exceptions³²) not in a position to ‘own and control’ their own research

³² Carlisle People First Research-team has accessed funding for its own project around self-advocacy and autism, (2004-5).

(Chappell, 2000). When people become included on academic funding panels and have access to research training, then the position may change.

Participatory research is certainly more empowering for people with learning difficulties, if:

- People are involved in the whole process
- People are learning about research skills to transfer to future projects
- Research support is based around ideas of empowerment and lessening dependency.

The ownership and control aspect of emancipatory research may be the ideal to head towards, but employing academic (and possibly non-disabled) researchers to carry out the research, at this time, will do little to change the position of people with learning difficulties. I contend that it is vital they become involved in research projects important to themselves. As the Carlisle People First Research-team (2004) explain, research needs to be about two things: a) the actual research; b) developing other people's awareness of research.

The deliberations around process are of the utmost importance to People First members and their groups (Andrew Lee, Chapter 8). Until these issues are addressed comprehensively, taking on board the magnitude of issues of access, a fully inclusive person-led approach to research and to the running of groups will be delayed. However, it is in the heart and minds, and also now in the experiences of a number of motivated people in self-advocacy organisations who share a

similar vision. As Geoff (Group A) remarked about the relationship between support-workers and members:

There should never be a 'them and us'. That's what we have been fighting against for a very long time. We need to share things, share the moment, share the excitement of things happening that are good. It's an equality thing, a human rights thing.

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APPENDIX ONE

Carlisle People First Research-team



Andy Docherty: Co-Chair of National Forum, Director of Carlisle People First
Interests: Institutional Life, Life History, Direct Payments.

Louise Townson: Project Director, Carlisle People First.
Interests: People with learning difficulties as supporters

Elizabeth Harkness: Citizen-advocacy Manager, People First Cumbria
Interests: Advocacy and Autism, inclusive education.

Malcolm Eardley: Campaign Worker, Carlisle People First
Interests: Anti- Bullying campaign.

Niall Mc Nulty: Young Persons Sexual Health Worker, Connexions
Interests: Young People and exclusion

Rohhss Chapman: PhD Student
Interests: Inclusive research and self-advocacy



APPENDIX 2

Different Types of Advocacy

Type of advocacy	How it works	Type of support
Self-Advocacy	Groups of people with learning difficulties speaking up for themselves	Generally an independent paid worker facilitating groups, providing information and assisting people in their choices.
Peer-advocacy	A person with learning difficulties speaking up for, and with their peer	Usually a long term independent friend or someone in the group who has had similar experiences
Citizen-advocacy	Generally a non-disabled person speaking up for and representing a person with learning difficulties. Long term and	Long term committed independent support in a voluntary capacity. Supported by advocacy organisation.
Crisis-advocacy	Generally a non-disabled advocate assisting and speaking up for a person in a crisis situation	Usually an independent paid worker, sometimes a volunteer who works short term. Will generally refer on to long-term citizen-advocacy
Circles of support	Where an individual (the focus person) may have difficulties in getting heard. The person chooses people who know them well to form a circle, which then assists the person in making choices and decisions.	Supported by facilitator of independent advocacy organisation. They help focus person plan meetings and ensures space given to all participants at meeting. Deals with arrangements and administration.

Source: Provided for staff of Walsingham, for training on advocacy, (People First Cumbria, 2003).

APPENDIX 3

Accessible introduction letter to Advocacy Group

October 11th 2001

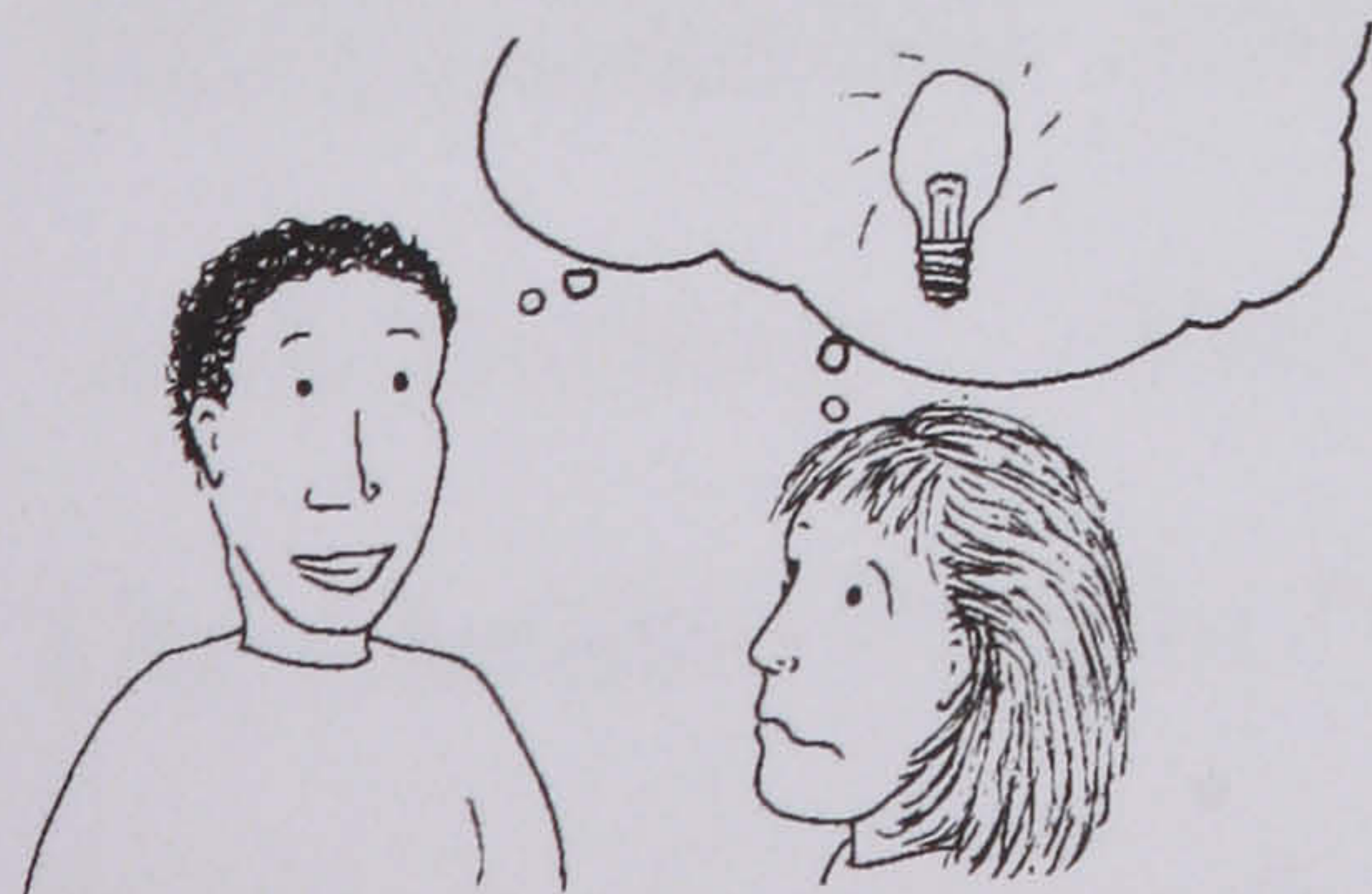
Dear Colleagues

My name is Rohhss Chapman. I am a research student at the Open University.



I used to be a support-worker at Carlisle People First so we may have met already. I am writing to tell you about some research that is being carried out about support-workers in the self-advocacy movement.

Support-workers work for self-advocacy groups. Sometimes they feel a bit unsure about the job they are doing and if they are doing it well. It can be a very enjoyable but sometimes difficult job. I am looking at how support-workers work with group members who employ them, how members view support-workers and what sort of influence members have over support-workers.



I am very interested in people with learning difficulties who are support-workers. The research is planned to be useful and helpful to self-advocacy groups in the future and any group taking part would get an accessible report of the research that takes place within their group.



I want to ask for permission to visit your group and talk to members and support-workers. I am planning to visit 6 groups in the UK. I am asking your group because you have been working at self-advocacy for over 10 years. That is a big achievement and people in your group will have seen a lot of changes.

The Research Group at Carlisle People First is supporting the work I am doing. They have done a lot of talking about support-workers that has helped plan this piece of research. They are also looking at the history of self-advocacy groups and we plan to join our work together. You may have heard from them already about their History Project. We are doing some of the work together.



Andy Docherty

Malc Eardley

Liz Harkness

Lou Townson

The Carlisle People First Research Group

The way the research is done will be open and friendly but confidential when you want it to be. I would probably need

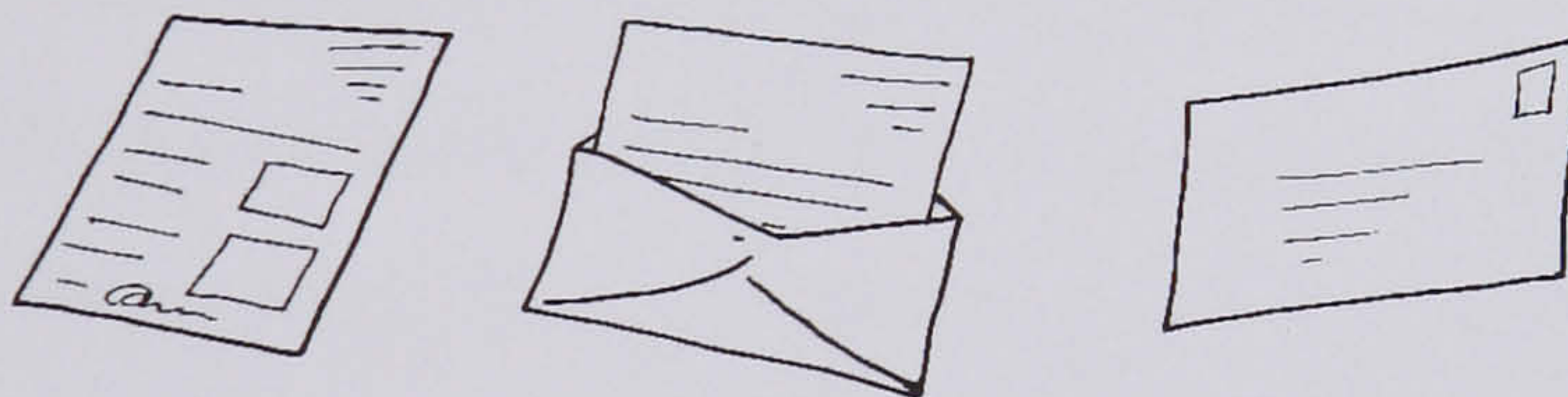
to be involved in your group in different ways for about 9 or 10 months.



If you feel that you are happy to let me work with you I will arrange to come and see you and talk about it a bit more.



I look forward to hearing from you if you could send me a note and post it back in the envelope provided.



If I don't hear from you within a few weeks I will ring to make sure you have this letter.

Yours Sincerely

Rohhss Chapman, PhD Student
Open University

phone:

07815 177180/ 01228 546345

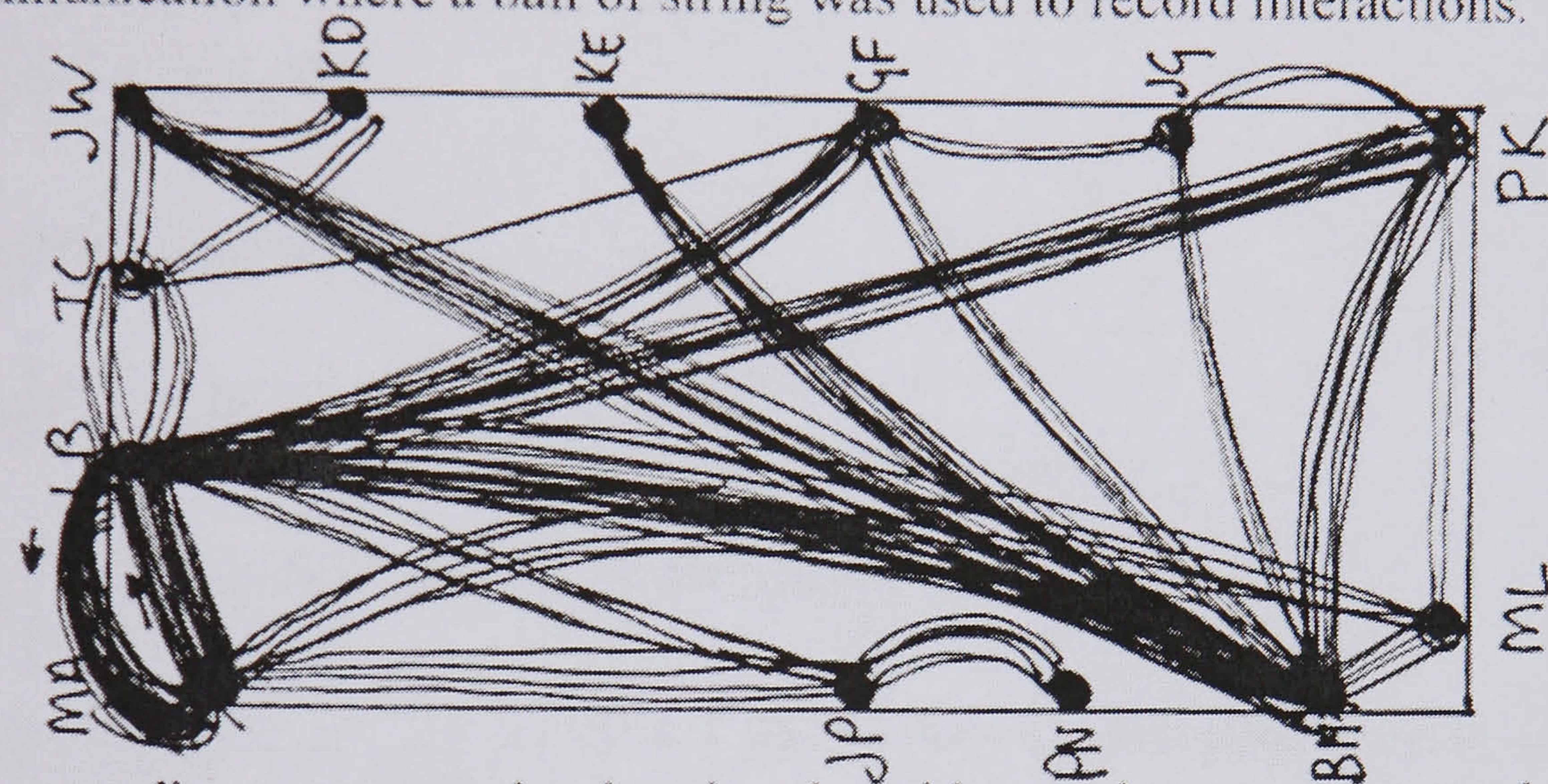
e mail:

r.chapman@open.ac.uk

APPENDIX 4

Communiograms

Communiograms were used to record interactions between advocacy-support workers and members at meetings. The first type was based on an exercise undertaken by Carlisle People First during a management training session on communication where a ball of string was used to record interactions.



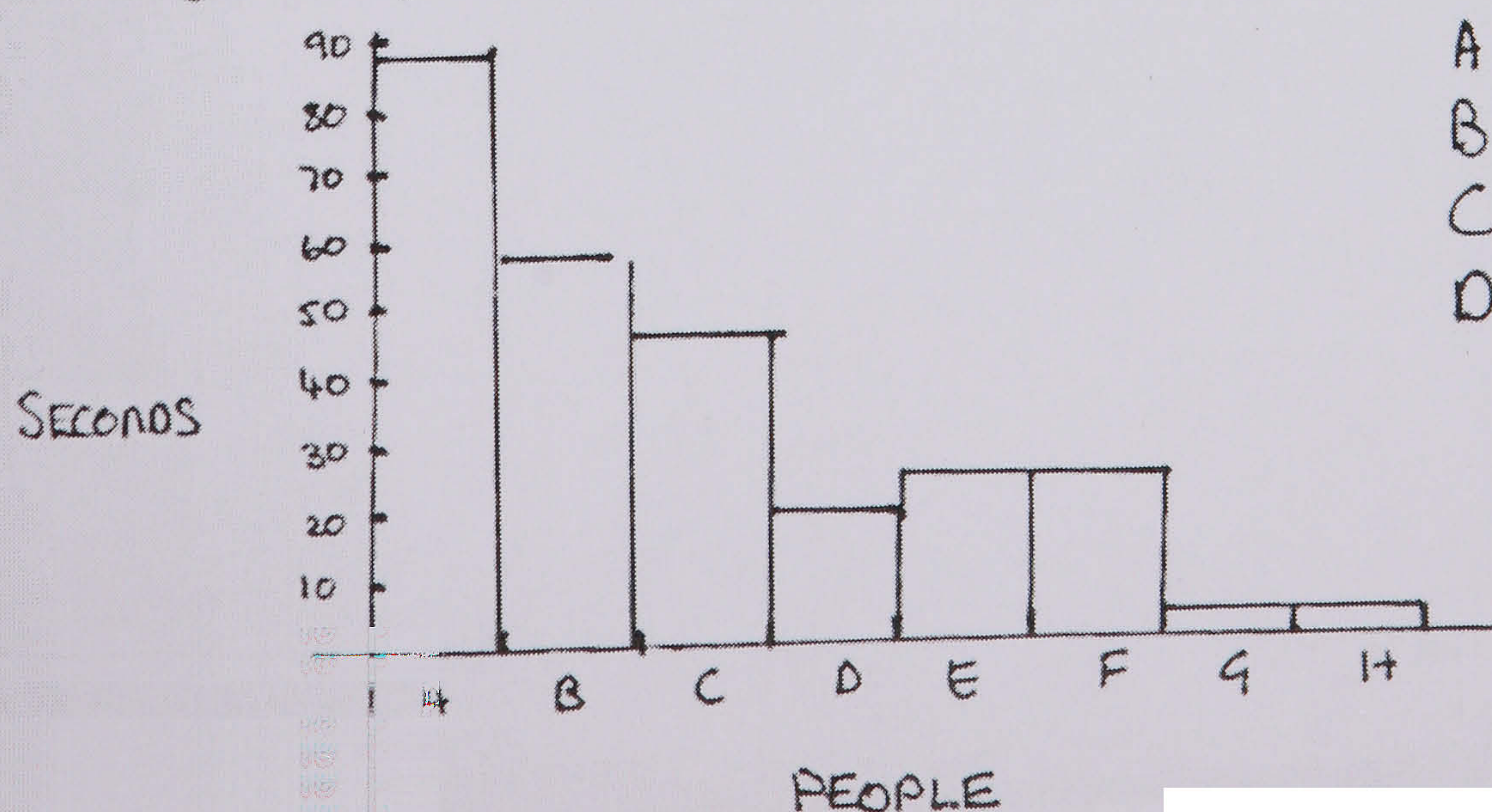
EXAMPLE

LB+MA =
Support workers

BM = Chairperson

The recording was set up by drawing the table people were sat around and then placing the initials of participants where they were sat. Each time a person spoke a line was drawn to the person it was directed to, or who answered next. The more lines coming from one person, the more interventions they made. In the case of Group A, at a management meeting, it was very clear that the support workers were doing most of the talking, and interestingly, a lot of that communication was between themselves. It could also identify who was not included in the meeting.

The second type of recording of interaction was made in graph form looking at the amount of time people spent talking. In Group C a graph of a diary meeting showed that advocacy support-workers not only made more interventions but also spent a longer time speaking.



A = Development Worker
B = Support worker
C = Chairperson
D-H = members

APPENDIX 5

Advocacy Support-worker 7 broad questions

General Questions for Support-workers Interviews

- Background
- Why this job
- Reflection of own power
- Barriers to SA
- Development over past 10 years
- Social model and People First model (if not mentioned already)
- Future

APPENDIX 6

Northwest Advocacy Support-workers Questionnaire, 1996.

SUPPORT-WORKER QUESTIONNAIRES 1996

1. When you first came into advocacy work what were your initial feelings over what it was about?
2. Why did you choose to become involved in the field of advocacy/people with learning difficulties?
3. Did you find the specific philosophy behind the People First movement difficult to understand or not?
4. How did you gather information about advocacy and People First?
5. How long have you been involved in advocacy/People First and what is your role in it?
6. Do you know feel you fully understand the philosophy behind People First?
7. What are your views about services providing advocacy as opposed to independent self-advocacy?
8. When you first entered advocacy work, what would have eased your initial few months in terms of information?
9. What has been the most significant help in your coming to understand the nature of advocacy work?
10. What do you feel are the highlights/advantages of being in advocacy work?
11. What do you feel are the major drawbacks of being an advocacy worker?
12. Do you ever have problems of your views conflicting with those of the people in the group?
13. Do you ever find yourself in a position where your support is being ignored? Do you have examples of this?
14. Have there been any particular problems you have come across in your work/
15. Is there a particular source from which problems arise or not?

16. Do you feel you fulfil the People First philosophy in the approach to your work?
17. What has your experience of other advocacy workers been? Do you get an opportunity to network with other advocacy workers?
18. How do you feel the advocacy group views you as an employee/ worker/ volunteer?
19. What do you feel are the most significant components of the People First Philosophy?
20. Are you involved in regular group work with people with learning difficulties?
21. Please list the main areas of your work (please enclose a job description if you have one).
22. How would you like to see your role as an advocacy worker develop?
23. In regard of your work now, what would be useful for you in terms of training or support?
24. Do you feel you have gained personally from your involvement in advocacy or not? Please explain.
25. What do you feel your personal rights are within your role?
26. Any further comments would be appreciated.
27. Would you be happy to participate in further research?

APPENDIX 7

Members questions

LOUS INTERVIEW QUESTIONS

BEFORE INTERVIEW:

1. What the research is about
2. Confidentiality.

INTERVIEW QUESTIONS:

1. How long have you been in the group?
2. Why did you join the group?
3. What is the group set up to do?
4. What is good support?
5. What is bad support?
6. How can members keep control of the group?
7. What is the future of the group?

APPENDIX 8

Pre- fieldwork meeting minutes

Group B Fieldwork: 20/5/02

Pre fieldwork meeting: Travel Inn 8-9pm.

(Visit to (Group B): Andy, Lou, Malc, Niall, Rohhss)

1. We talked about the role of observer. This covered:
 - Respect for the host organisation
 - What to say if questions were asked
 - What to look for: issues around power and support
 - Just being there and seeing what goes on
 - Confidentiality
2. We reminded ourselves of the role of the interviewer. This covered:
 - The reasons for interviewing
 - Confidentiality
 - Support if required
 - The interview process (Lou talked about her experiences of interviews in Group C)
 - The interview questions
 - Who would be interviewed
 - Name change for anonymity.
3. Lou talked about the importance of doing your fieldnotes as soon as you got back so you don't forget anything. We agreed not to talk about it to each other until we had done our own notes to avoid influencing each other. The process we use is:
 - Do your own fieldnotes (or dictate them)
 - Write a reflection of the interviews
 - Get someone to read the fieldnotes and ask further questions
 - Make these extra pieces of information clear in italics.
4. Niall discussed his role tomorrow: supporting people to undertake research.

5. We discussed what we already knew about (group). I read their mission statement and talked briefly about the main job roles.
6. Andy asked if we were judging them. This led to conversation about how being a researcher was not to judge but to record what was happening. Analysis would happen at a later date.
7. We talked about who was doing what and why.
 - Lou to observe and interview members
 - Andy to observe and interview. He asked for support from Niall.
 - Malc to observe and look through paperwork. He did not offer to interview but reminded us that he was an experienced interviewer already having done the research on his book.
8. People seemed to feel comfortable and said they were looking forward to doing the research tomorrow.

APPENDIX 9

Example of graphic illustration from research planning group

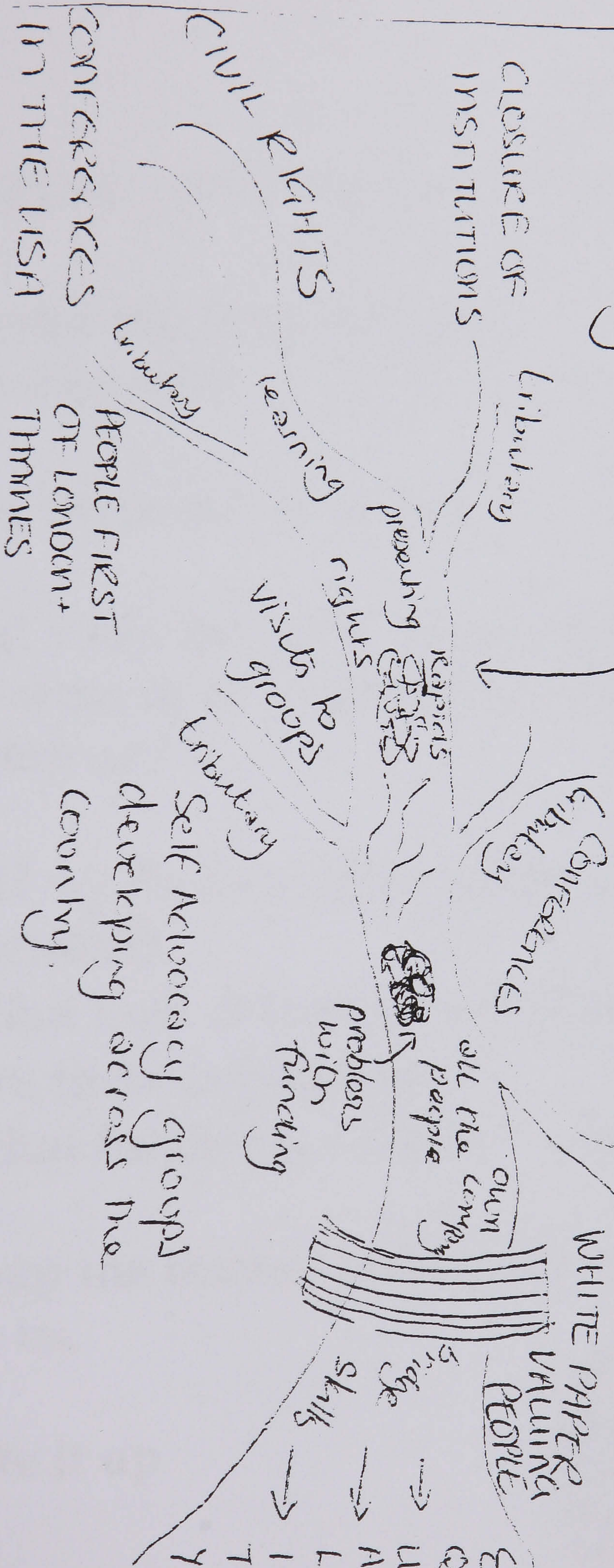
23/02/01. Research Planning Group

revised
history.

Attempts to set up
England People First

dead end

Effects at National Organisation



The Illisnoel Flow through the self-advocacy movement as a river. Ideas of the Research Planning Group.

APPENDIX 10 ANALYSIS

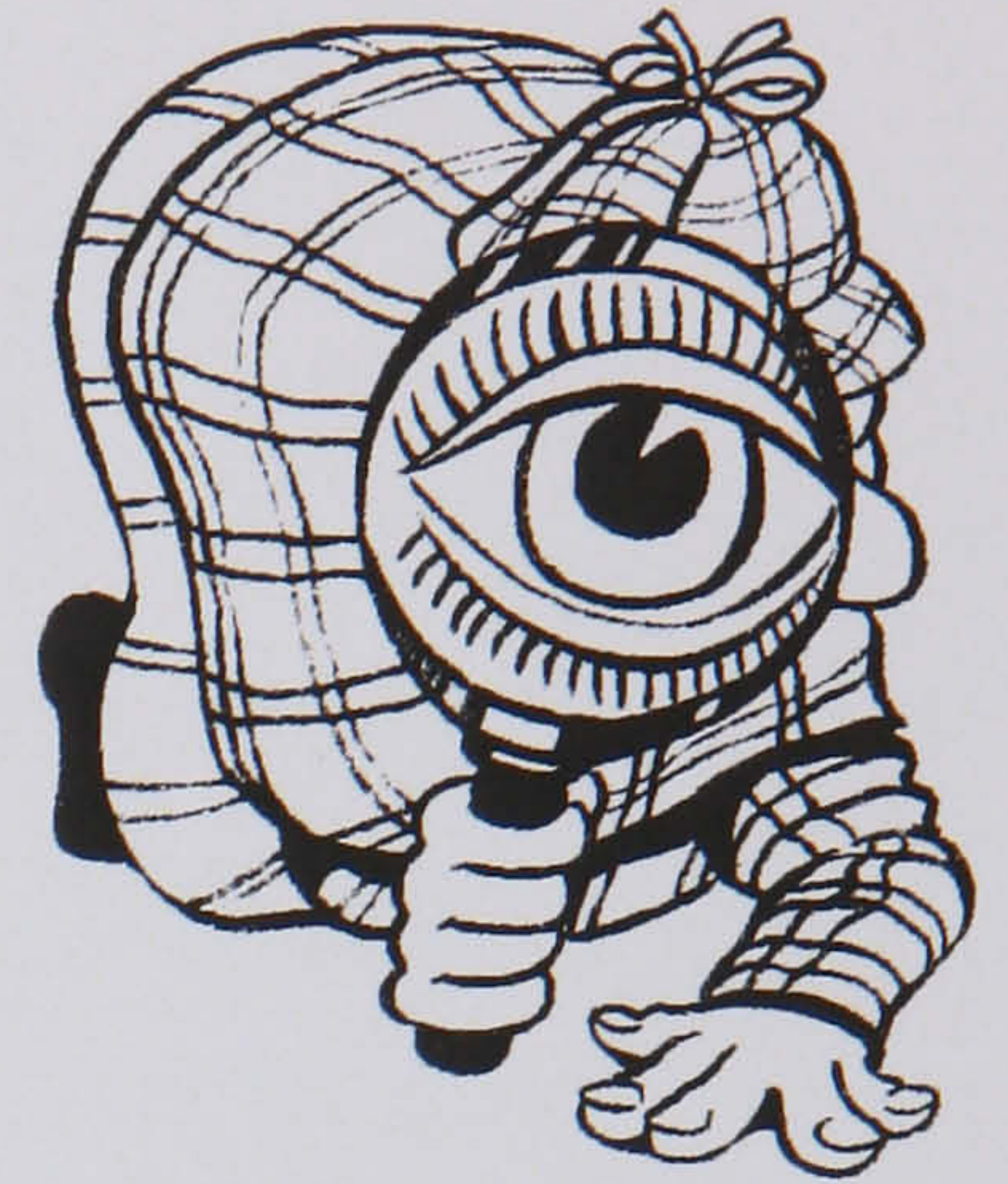
a) ANALYSIS MEETINGS

Agenda

WHAT HAVE WE FOUND OUT?

1. How did the fieldwork and interviews go?
2. Were there any problems?
3. What were the main things we heard or saw that seem to be important. What kept coming up?
 - Did we find anything surprising or unusual?
 - What does this make us think about?
 - Are there connections?
 - What further questions could we ask?
4. Group the themes and decide what it all tells us.

Write it up



APPENDIX 10

b) Themes from Group B analysis. Session 1: 18/1/02

(taken as copy from flipchart used during analysis session)

Ones we identified before:

1. Not being believed
2. Swept under the carpet
3. Bigger fish to fry.

Themes that emerged as new:

4. Barriers: Lack of physical access in building and to written word
5. Run down building
6. Support worker power in relation to member power:
 - Resistance to member as tutor
 - Control of office design
 - Information coming in filtered by support workers
7. Image (member presented in more positive light than seen in reality...why?)/ models of support?)

Group B Analysis meeting: Session 2: 13/1/03

Where did we get to?

Themes around physical environment/ process issues.

What comes up today?

8. Who has control in the office? (Use of diagram)

9. Who is running the group?

10. Lack of funding

11. Uncomfortable role (Support worker says three times 'I shouldn't really be saying this but...')

**NOTE: Themes brought forward that were to be explored:
(See chapter 6 to link)**

- **Models and theories (7, 11,)** *SRV, image, People First, supporters as teachers (Andy thinks they were putting on a show)*
- **What advocacy workers should do (6, 8, 9, 11)** *written documentation, power given to support workers*
- **Emerging barriers (4, 5, 10)** *Shared plan? Information not getting through*
- **Issues around funding (10)**

APPENDIX 10

c) Analysis Group B Meeting notes, session 3 Interview with Donna

*She did supervisions (A)

The support workers support what they want to (M)

Where does the funding come from? (A)

*There's not many people involved with a learning difficulty, they don't do the supervision (L)

They don't seem very well structured (A)

The job descriptions need to be flexible, I don't like, 'I fell into the job'. (L)

It seems tokenistic. *She is making a decision about things and then going to get approval. Rather than giving information, choices, and having a full discussion (L)

*Donna is going to the courses, getting the information and bringing it back to the group. Why not get the members to go? (E)

Is there a tension between the things she does and the model of People First in her mind? (R)

*The training is not fully accessible (M)

She is being a supporter as a leader. She says, 'my group' (L)

*Only two people with a learning difficulty are on the management group. How can that be a people first group? (A)

*Donna does all the funding. How will the group learn? (E)

* Emerging points that could be directly evidenced and used as quotes to illustrate the themes.

APPENDIX 10

d) Themes for analysis 15/08/02

(Bringing different group's analysis together)

People are not included

Planning day (C)

Funding strategy (D)

Who are on the management committee (B,D)

Exclusion within disability movement (A)

Words misrepresent situations and maintain power

What people first tells us (D)

I was asked to... (A)

National Forum support

Poor quality venues and locations

Links to SRV theory, imagery

Group A meeting place,

Group B office

Group D office

Buildings, arrangement and space exclude people

Environmental

Lack of a plan

No guidance (B,C,)

Plans made by others ((A,B,C,D)

Lack of mention of social model (B)

Mention of social model but not sure if understood (A)

People are not believed

Service complaint-making (B)

Support in ATC (B)

Experiences (B,C,D,E)

Important things are trivialised

Different attitudes towards supporters and members (B, A)

Resistance to support and teaching by members (B)

Members issues (A, C)

APPENDIX 11

Audit trail of dates of fieldwork visits to groups

Group A	January 2002
Group B	March 2002 and May 2002
Group C	April 2002
Group D	June 2002
Group E	February 2003